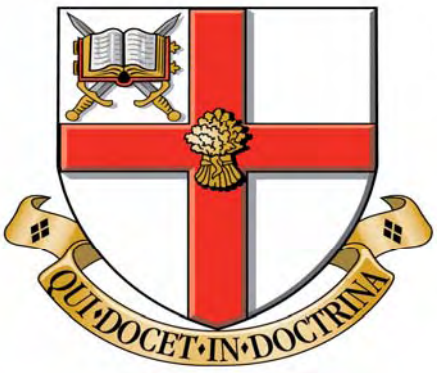

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An investigation into pregnant women's knowledge of prenatal screening: implications for service provision.

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ABSTRACT

Informed consent is one of the legal-ethical cornerstones of our health care system and is central to health care decision making. The ability of clients to make informed choices regarding their care is dependent upon the information imparted to them by health professionals, and also upon the client's subsequent understanding of such information. The issue of informed consent in relation to prenatal screening can be problematised because it requires consideration of complex moral and ethical issues, and the ability of clients to make informed choices is dependent upon the attitudes, knowledge base and communication skills of the health professionals who offer screening.

In order to discover how much pregnant women know about prenatal screening tests, a cross-sectional survey using structured interviews was undertaken with a cohort of two hundred pregnant women who were offered prenatal screening. The knowledge possessed by each individual regarding maternal serum screening for Down's syndrome and ultrasound scan for fetal anomaly, was measured and subsequently analysed to ascertain if there was any relationship with their age, social class, parity and whether counselling was received by a hospital or community midwife. The scores obtained resulting from the knowledge possessed by each individual regarding both tests were further subject to statistical analysis to assess if participants were more knowledgeable regarding either the practical aspects or the implications of testing. Data regarding how each test was offered was also collected. Furthermore, participants cited the health professional whom they considered to have given the most useful information, and these data were analysed to assess if this had influenced the clients' knowledge base.

The study concludes that pregnant women in this study are significantly more knowledgeable about maternal serum screening, than they are in relation to ultrasound scan. The levels of knowledge regarding both tests are significantly higher in the older age group and the professional group, suggesting that age and social class are strong demographic indicators of knowledge. Furthermore, participants are significantly better informed regarding the practical aspects of screening and demonstrate a lack of understanding regarding the more complex implications of screening. The source cited as having provided the most useful information (midwife, doctor, media or family and friends), is not an indicator of knowledge. It also appears that greater efforts are being made to present information on maternal serum screening to clients, indeed many participants failed to receive any verbal or written information regarding ultrasound scan.

In order to facilitate and enable pregnant women to make informed choices regarding prenatal screening, it is proposed that they possess an understanding of both the practical aspects and the potential implications of being tested. Recommendations are made, which include the employment of a health professional whose specialist role would involve the co-ordination and monitoring of screening programmes. Furthermore effective staff training must address the individual and psychological needs of both staff and clients in respect of the complex and sensitive issues that accompany screening. Moreover, in order to guide health professionals in their clinical practice, a sound understanding of the ethical principles which underpin screening procedures is indicated.

"Women told us they felt pressurised to have tests and that once they were labelled 'high risk', it was a slippery slope to amniocentesis and possible termination of their pregnancy. What they wanted was information and a chance to discuss their choices with someone who knew what they were talking about, not assumptions that they would follow standard practice or routine care."

(Rosemary Dodds, 1997).

DECLARATION

This work is original and has not been submitted previously in support of any qualification or course.

Diane L. Lee.

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CONTENTS

LIST OF ABBREVIATIONS

RCOG	-	Royal College of Obstetricians and Gynaecologists
DoH	-	Department of Health
MSS	-	Maternal Serum Screening
USS	-	Ultrasound Scan

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CHAPTER ONE

INTRODUCTION

As we approach the millennium, health care professionals are becoming increasingly involved with screening healthy populations for disease and risk of disease. This is particularly true of those implementing antenatal care services. Advancing technology, increasing expenditure on health, and financial incentives for general practitioners to offer screening tests, have resulted in large numbers of people being screened for medical conditions, over greater spans of their lives (Marteau, 1990).

Antenatal clinics now offer pregnant women screening tests for fetal abnormality. These include fetal anomaly scans to detect structural deformities, and maternal serum screening for Down's syndrome. The analysis of these investigations give obstetricians the opportunity to investigate unborn babies for possible abnormalities with the objective of identifying any problems early in the pregnancy. In this way termination may be a feasible option or possible effective management might be offered. As a result, abnormalities which previously would have gone undetected until after the birth, can now be identified, presenting parents with questions and anxieties not previously encountered.

In order to meet the objectives of prenatal screening for fetal abnormality, health professionals must ensure that parents make informed decisions about having the initial screening test, and understand the possible implications of the test. The factual, social and psychological aspects of prenatal screening, have presented those involved with implementing these tests with the challenge of enabling clients to give informed consent. Indeed, this work aims to problematise the concept of informed consent by investigating how

much pregnant women know about the screening tests which are offered to them. Furthermore, Marteau and Slack (1992) suggest that the issue of enabling pregnant women to make informed choices regarding prenatal screening has been overlooked in the recent rush to implement screening programmes, resulting in raised anxiety and false reassurance. It is therefore important not to assume that technological advances and the subsequent development and offering of screening programmes, universally bestow positive benefits upon those who undergo the procedures:

> "The way an effective screening test is implemented will influence how much good and how much harm it does".
>
> (Marteau, 1990, P.26)

It is widely agreed that on the basis of good information, pregnant women should make their own decisions regarding test uptake (Royal College of Obstetricians and Gynaecologists, 1993). Indeed Changing Childbirth and The Patient's Charter (Department of Health, 1993; 1992) emphasise 'women-centred care', where each individual takes on the responsibility for making her own decisions regarding her care. However Proud (1995) stresses that women cannot be in a position to make informed choices concerning their care, without being in the possession of information necessary to make those choices. Therefore, there is an expectation that midwives and obstetricians will give women a full explanation of any prenatal screening tests that may be offered. The Royal College of Obstetricians and Gynaecologists (1993) state that this should include what the test involves, particularly the conditions it may detect, the likelihood of detecting the condition, possible risks incurred, when and how the results are available, the risks and limitations of further investigations and where further information may be sought. A further reason for informing women about screening tests is to prepare them for the potential of adverse outcomes, such as being

recalled for further tests. This implies full explanation of the potential for and the meaning of both positive (high-risk) and negative (low-risk) results.

The key concept relating to this study is that of informed consent and its implications for service provision. Purtilo (1993) states that the doctrine of informed consent is founded on legal-ethical principles and is a procedure which entails a process of decision making, where clients can either consent to or refuse medica3 intervention, based on information provided by health care professionals regarding the nature and potential implications of the proposed treatment. She moves on to suggest that enabling clients to make informed choices is dependent upon the communication, listening and interpretive skills of the health professionals involved. Furthermore, she points out that bringing the client's informed preferences into health care decisions, allows health professionals to practice in a morally defensible way.

Coy (1989) states that from a legal and moral perspective, the aim of informed consent is to enable the patient to make important decisions regarding his or her health care, thereby ensuring that medical intervention will serve in the patient's best interests from his or her perspective. Purtilo (1993) also describes informed consent as a relationship of special trust between the health professional and the client, with the aim of protecting the client's dignity. Rumbold (1993) makes the distinction between informed consent where clients receive information from health professionals, and educated consent which refers to the client's understanding of the given information, in order to make a reasoned decision. However, the purpose of this study is to focus upon pregnant women's knowledge of prenatal screening and not how they come to such an understanding. Therefore the concept of educated consent may be reserved for future study.

The notion that patients have a right to give or withhold consent to treatment as a result of informed decision making, is historically a recent one (Rumbold, 1993). Indeed Veatch (1981, cited in Rumbold, 1993) states that traditionally the Hippocratic physician abides by the doctrine of 'therapeutic privilege' where the physician withholds information from the patient because he or she considers this to be in the best interests of the patient. However, Rumbold (1993) points out that the judgements made in the courts and laws passed by governments, reveal that twentieth-century society has rejected this view. He states that the most important legal concepts which are pertinent to informed consent are battery, disclosure and the fiduciary relationship, and the common law right to self-determination and constitutional right to privacy. Battery is an act of offensive touching performed without the consent of the recipient, however benign the motive or effects of the action. Disclosure involves a person's right to be informed of what will happen to him or her, and the fiduciary relationship embraces a relationship where a person in whom another person has placed trust or confidence, is required to serve the best interest of the other party.

Proud (1995) points out that the ability of pregnant women to make informed choices regarding prenatal screening is dependent upon their knowledge and understanding of such tests. It is therefore reasonable to suggest that the knowledge base possessed by health professionals in relation to screening, and their skills in presenting information to clients in a clear and understandable manner, will directly influence the ability of pregnant women to give informed consent. Indeed a study by Marteau et al. (1992) proposes that health professionals do not possess adequate knowledge or communication skills to effectively present information to pregnant women regarding prenatal screening. Furthermore Proud and Murphy-Black (1995) indicate that there are health professionals who are paternalistic

in their approach to offering clients prenatal screening, and are withholding information from clients because they feel this would serve in the best interests of the client. Moreover, the issue of informed consent in relation to prenatal screening can be further problematised because it requires clients to consider complex moral and ethical issues, before they can make a decision which truly reflects their desired intention.

The governing ethical principle in informed consent is the right to self determination or autonomy. An awareness of the ethical principles which underpin the doctrine of informed consent will help to guide professional practice. Naidoo and Wills (1994) emphasise the point that the decisions of an individual are derived from personal values and moral beliefs which results from religion, culture, ideology, or professional codes of practice, or social etiquette, the law, or life experience. Thus ethical theory does not seek to provide definitive answers, but serves to guide individuals on whether certain actions are ethical or not. Most mainstream ethical theories fall into two categories - deontological and utilitarian.

Autonomy is a principle of deontological theory which underpins informed consent. From a deontological perspective, there is a duty to follow universal moral rules which state that actions are either right or wrong, irrespective of any good consequences produced or bad consequences prevented, thus considering the worth of each individual. Within this theory, people are treated as ends in themselves and not a means to someone else's ends, that is, treating others as one would wish to be treated oneself. The principle of autonomy involves respecting the rights of individuals and their right to determine their own lives. Faulder (1985) describes autonomy of thought, speech and action. Autonomy of thought embraces counselling, where information is given and the client is able to talk through and consider the issues, in order to make a decision. Autonomy of speech involves the client being able

to discuss their options without the imposition of restrictions or conditions; and autonomy of action allows the client to feel comfortable and respected for the decision they have made, irrespective of whether the health professional approves of their judgement or not.

Beauchamp and Childress (1989, cited in Naidoo and Wills, 1994), describe three further ethical principles which provide a framework for consistent moral decision making:

- Beneficence - doing or promoting good.
- Non-Maleficence - doing no harm
- Justice - being fair and treating equal people equally.

Naidoo and Wills (1994) state that most preventative services are offered on the understanding that they will do good and not harm, but what is the nature of 'good'? Indeed, traditionally the biomedical model defines good as the absence of disease. Moreover, prenatal screening can only indicate that the fetus appears to be healthy at that time, unless further definitive diagnostic tests are undertaken. A negative result does not mean that the baby is guaranteed to be born free from abnormality, thus screening cannot promise a favourable outcome. Naidoo and Wills (1994) view screening as a representation of the tension between beneficence and non-maleficence, that is, it is seen as good, but not necessarily without harm. As a result, Duncan (1990) argues that screening must involve the client being fully informed of the benefits and disadvantages of testing. Purtilo (1993) suggests that client autonomy must be the key to informed consent. However, the giving of such information involves complex ethical decisions, thus Seedhouse (1988) identifies truth telling and promise keeping as key principles for giving such information. Thus it is possible to suggest that although health professionals may not universally agree on the nature of

'good', or be able to guarantee a favourable outcome, they are acting in the best interests of the client by enabling them to make informed choices.

Naidoo and Wills (1994) view autonomy not as absolute, but as attainable to a greater or lesser extent. The autonomy of an individual may depend upon the sense of responsibility to others and the ability to understand and act upon one's environment. Furthermore, Seedhouse, (1988) makes the distinction between creating and respecting autonomy. The creation of autonomy involves enabling people to make decisions, perhaps by increasing self-awareness, assertiveness and developing analytical skills. Seedhouse (1988) moves on to define respecting autonomy as allowing the client to feel comfortable with his/her decision, even if the health professional does not approve. For example, the view of a doctor may be derived from the biomedical model, where the termination of an abnormal pregnancy would be indicated. However, a pregnant woman may view such an abnormality as very unfortunate, but not necessarily indicating termination. Indeed, the dilemma of control on behalf of the health professional and autonomy of the client was illustrated in a study by Proud and Murphy-Black in 1995. Midwives admitted to answering queries posed by the clients, but did not volunteer further information regarding testing, thus ensuring that power and control remained with the midwife, thereby contravening the personal autonomy of the client. It was also evident that certain information was withheld with the intention to act in the woman's best interest, for fear of generating anxiety regarding fetal abnormality. Naidoo and Wills (1994) state that such an attitude is paternalistic and places the health worker's commitment to 'doing good' above the client's wish for autonomy.

Utilitarianism is the best known branch of the other classical school of ethics known as consequentialism and Proud (1995) states that it has traditionally underpinned the operation of screening programmes by following the biomedical model of health. It differs from deontological theory because it is concerned with the end justifying the means. The objective is to produce the greatest happiness for the greatest number, thus utilitarians respond to moral dilemmas by reviewing the facts and weighing up the consequences of each option. Naidoo and Wills (1994) warn that this is problematic because of the difficulties in defining a good end, and predicting whether an outcome will be favourable or not. Moreover, in the attempt to produce the greatest good, can this justify harm or injustice to the lesser number? Key philosophical questions arise from this issue about freedom and its limits, specifically, should the interests of the majority always take precedence over those of each individual? High levels of anxiety have been reported in patients participating in many screening programmes (Marteau, 1989). Maternal serum screening is known to produce a five percent false positive rate (Wald, 1994), and Stratham and Green (1993) emphasise the psychological problems encountered by pregnant women who receive such a result. Such evidence questions the morality of prenatal screening by reinforcing the argument of Naidoo and Wills (1994), who ask if the harm inflicted upon this minority can be justified by the benefits enjoyed by the majority. Future efforts to improve the implementation of prenatal screening programmes should therefore be guided by deontological theory, where the key ethical principles of informed consent include a combination of the client's right to self-determination, and the health professional's duty of non maleficence as specified by the Professional Code of Conduct (UKCC, 1994).

Observational studies indicate that midwives and obstetricians often provide very little information about prenatal screening tests and that the information given is sometimes inaccurate (Marteau et al., 1992, 1993). A study by Smith et al. (1994a) suggests that pregnant women lack knowledge about aspects of serum screening that could both inform their decisions regarding test uptake, and prepare them for the possibility of being recalled with a high-risk result. Indeed the psychological consequences of failing to prepare women for this event, can lead to increased anxiety states and negative attitudes towards the pregnancy (Stratham and Green, 1993; Marteau, 1993).

These problems were evident from clinical practice experience at Chester, and in the light of previous literature, it was decided to design a study that would identify whether or not pregnant women who were offered prenatal screening at Chester had the knowledge and understanding which is needed to make informed choices regarding test uptake. The aim of the study was to discover what pregnant women know about maternal serum screening and ultrasound scan, by highlighting areas of good and poor knowledge. Thus future recommendations may be proposed to optimise the ability of clients to make informed choices regarding their care. For the purpose of this study, the information collected is referred to as the key issues relating to maternal serum screening and ultrasound scan. It should be stressed that this information is recommended by the Royal College of Obstetricians and Gynaecologists (1993), and not by the women themselves. The subsequent comparison of this knowledge with respect to age, social class, parity and whether counselling was provided by a hospital or community midwife, would further define the problem areas, potentially enabling services to be improved by targeting high risk groups. Furthermore, the collection of data regarding certain practical aspects of how the tests were offered would facilitate the overall objective of making amendments to current practice regarding the

implementation of prenatal screening services at Chester. It was thought that the study would therefore inform how and where any changes should be made, in the attempt to facilitate informed decision making at all stages of the screening process. Thus, good practice in professional development is sought by pursuing the attainment of optimum standards in the counselling of pregnant women regarding prenatal screening. It was felt that the study will further inform and develop knowledge within this field, because it proposes to assess directly the knowledge women possess, using structured interviews, rather than employing observational study as seen previously. In this way, it is acknowledged that women do not use information obtained from health professionals in isolation, and that other sources such as the media, family and friends will inevitably bear an influence upon their knowledge base.

In order to appreciate the importance of the issues and the magnitude of the problems that can be created as a result of testing, it is necessary to briefly outline maternal serum screening and ultrasound scan procedures.

MATERNAL SERUM SCREENING

The aim of maternal serum screening is to identify pregnancies with a sufficiently high risk of being affected by Down's syndrome, to justify the offer of a diagnostic test such as amniocentesis. This is achieved by measuring biochemical markers in the maternal blood at fifteen to sixteen weeks gestation, and the subsequent analysis with maternal age, to estimate a risk of Down's syndrome for that pregnancy. Should that risk be greater than a specified cut-off level (usually 1 in 250), then the woman is considered to be in a high risk group or screen positive, and is offered amniocentesis. As well as the general anxiety

inevitably caused by screening, inherent within maternal serum screening are several problems. There exists a false positive rate of five percent of the screened population (Kennard et al., 1995), who will subsequently be offered amniocentesis to determine if the fetus is in fact affected by Down's syndrome. This procedure incurs a one percent miscarriage risk (Kennard et al., 1995), and the results can take up to four weeks to process. This has implications regarding the psychological effect of waiting so long for results, and the fact that termination of pregnancy cannot be offered until around twenty weeks gestation. Ultimately, the test achieves a detection rate of around sixty percent, therefore there exists a certain population who will be screened as low risk, only to deliver an affected child (a false negative). However, the test does offer some advantages. In the past, all pregnant women over thirty-six years of age were routinely offered amniocentesis because of their increased risk status. However, this only achieved a detection rate of less than one-third. Now by offering serum screening to all women, it is possible to detect two-thirds of affected pregnancies for the same numbers of women undergoing amniocentesis (Wald et al., 1994). In this way, high risk women from the lower age groups can be offered amniocentesis, whereas low risk women from the higher age groups, may be spared the risks incurred by amniocentesis.

ULTRASOUND SCAN

Sound waves with a frequency over 20,000 Hz are called ultrasound. They can be generated by passing a high voltage through a crystal and causing it to vibrate at a high frequency. Sound waves are emitted then formed into a beam and directed onto the mother's abdomen using a probe. Whenever the beam crosses a boundary between two tissues of differing properties, it is partially reflected back to the crystal. The crystal (or transducer)

subsequently converts the sound into electrical energy, which can be viewed as an image on a monitor or screen.

The objectives of ultrasound scan are to assist in the reduction of perinatal mortality and morbidity. The majority of anomalies occur in apparently low risk women, therefore universal screening is the only effective method by which these abnormalities can be identified (Whittle, 1991). Furthermore, ultrasonography may identify a fetus in need of in-utero treatment or a fetus that will need immediate surgery following birth. Some argue that the routine use of ultrasound in pregnancy has never been evaluated (Robinson and Beech, 1993), and can reveal information that women may not wish to know (Stratham and Green, 1993). Research suggests that frequent ultrasound of the fetus might be harmful (Newham et al., 1993; Salvesen et al., 1993); indeed there is no evidence to suggest scanning is absolutely safe (Robinson and Beech, 1993).

Ultrasound scanning is viewed very positively by most women, especially when they can share the sight of their unborn baby with their partner (Proud, 1995). However, since it can produce information which may indicate palliative treatment or termination of pregnancy, it is vital that women fully understand the implications of this procedure.

It is necessary to put prenatal screening into context by discussing what is meant by 'health' and briefly examining the issues and ideologies which underpin the contested concepts of health education and promotion. Definitions of health have arisen from many different perspectives, indeed attempts to produce an overall definition is the subject of much debate (Pike and Forster, 1995).

> "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."
>
> (World Health Organisation, 1946)

This definition is criticised by Pike and Forster (1995) for being unrealistic in suggesting a state that very few could aspire to. The assumption that one particular state equals health fails to address life's constantly changing demands, expectations and stimuli. A further criticism of this definition is that someone, somewhere, has the right and ability to define health, despite the fact that each individual's perception of health is shaped by his or her knowledge, experiences, values, expectations and social or cultural situations (Ewles and Simnett, 1995). However this definition can be credited for embracing the notion of positive health (the presence of well-being), and distinguishing this from the negative definition of health (the absence of ill-health and disease). Furthermore, it acknowledges the importance of social and mental well-being, thus moving away from the traditional biomedical model by introducing the concept of the whole person, rather than giving sole consideration to purely physical problems (Ewles and Simnett, 1995).

Consideration of mental well-being is pertinent in relation to prenatal screening because there is evidence to suggest that the psychological implications of screening are frequently neglected, resulting in high levels of anxiety amongst the screened population (Marteau, 1990). Seedhouse (1986) proposed that health is a foundation for achieving a person's real potential, and Mansfield (1977) describes "empowering" people to reach their full potential, thus linking health with improving quality of life. Indeed, the concept of empowerment can be related to giving pregnant women detailed information in relation to both the practical aspects and the implications of screening. An understanding of this knowledge therefore

empowers women to make informed choices regarding prenatal screening and Marteau (1993) suggests that this can reduce the anxiety associated with participating in screening programmes.

Authors have eloquently argued that the NHS has been over-medicalised and obsessed with the physical and technological aspects of health care (Illich, 1976; Navarro, 1976). Indeed this view is echoed by Marteau et al. (1992) who stated that the amount of resources dedicated to the development of new technology regarding prenatal screening procedures, far outweighs the amount given to considering how best to implement such tests into clinical practice, resulting in the failure to address the potential psychological effects of screening. Although biomedicine has achieved a great deal, Illich (1976) stresses the virtue of responsibility for self and group members. He criticized the biomedical model for making us dependent on professionals, thus rendering us incapable of handling pain and suffering. Illich argues that instead of healing, biomedicine actual creates illness, that is, iatrogenesis. He insists that for the most part medicine is itself a major impediment to the achievement of health.

> "Increasing and irreparable damage accompanies present industrial expansion in all sectors. In medicine this damage appears as iatrogenesis. Iatrogenesis is clinical when the pain, sickness and death result from medical care; it is social when health policies reinforce an industrial organisation that generates ill-health; it is cultural and symbolic when medically sponsored behaviour and delusions restrict the vital autonomy of people by undermining their competence in growing up, caring for each other, and ageing, or when medical intervention cripples personal responses to pain, disability, impairment, anguish and death."
>
> (Illich, 1977, P.271).

To relate this to prenatal screening, it is cultural iatrogenesis which is characterised by the undermining of womens' autonomy, when health professionals do not ensure that clients fully understand the issues relating to screening, before making health care decisions. Illich makes the point that health is a process of adaptation, which is dependent on personal autonomy and such autonomy can be obstructed when an individual cannot choose his or her response because, through ignorance, he or she is in no position to do so. Indeed, screening has traditionally been based on the biomedical model of health so fervently criticised by Illich and practice has not evolved to develop procedures that take into account other definitions of health.

The Health of the Nation (Department of Health, 1992) attempts to redress the balance by stating that health education should aim "to ensure that individuals are able to exercise informed choice when selecting the lifestyle which they adopt". This involves providing people with information to facilitate informed decision making. Such an approach represents a swing away from the more traditional utilitarian ideology, towards a more deontological philosophy. Indeed, traditional health education had previously entailed giving information to clients in line with an authoritarian ideology. A new type of health education is now evolving, where clients are not only given the required information, but are supported by a health educator throughout the decision making process without coercion or persuasion. For the purpose of this study this is defined as the empowerment approach to health education. Whilst Tones (1990) states that the aim of the empowerment approach to health education is to bring about a change in attitude or skills, French (1990) opposes this by suggesting that overt behavioural change is not the prime intention.

Naidoo and Wills (1994) state that one of the paradoxes and a prevailing dilemma resulting from health education, is the question of voluntarism or free choice. On the one hand, traditional health education has evolved from both medicine and education and is based upon an authoritarian model, where the health educator identifies a health need, recommends intervention and attempts to ensure compliance regarding the information given. On the other hand, many health educators do not view clients as "empty vessels" who will change their behaviour once given the relevant information, advice or guidance. Naidoo and Wills (1994) emphasise that in line with this philosophy there is no attempt to coerce or persuade because it is unlikely to be effective and is unethical. Instead of telling the client what to do, the empowering health educator facilitates the process of identifying clients' needs in working towards an informed choice. Indeed this ideology is a key recommendation of Changing Childbirth (Department of Health, 1993), which advocates that pregnant women should be enabled to make decisions regarding their pregnancy care with the appropriate advice, support and guidance from health professionals. Tones (1992) states that the principle of self-empowerment is central to the practice of the empowerment approach to health education and has evolved from the debate regarding voluntarism and authoritarianism. It involves enabling people to take charge of their lives and change their behaviour, if they so wish.

The principles of traditional health education were challenged by those of health promotion which were presented in Ottawa Charter (World Health Organisation, 1986), and later further defined in 'Health for All' (World Health Organisation, 1993). These documents differed from the traditional biomedical model of health by emphasising the movement away from the prevention of specific diseases and the detection of high risk groups, towards the health and well-being of the population as a whole. Instead of health being viewed as the responsibility of individuals alone, the social factors affecting health were considered, thus health is seen

as a collective responsibility of society, involving environmental and political action. Indeed, health education remained an essential activity, but was located within a broader political spectrum. Thus the empowerment approach to health education is set in the context of 'developing personal skills' and moves from a patriarchal activity based on utilitarian principles, to an empowering one based on deontological principles.

However, 'individual victim blaming' as seen in traditional health education practices fails to acknowledge how social context influences the ability of individuals to make healthy choices. In fact Naidoo (1986) blames the individualistic ideology of traditional health education for its relatively poor performance. She suggests that individualism fails to address the real issues associated with health and illness because "it ignores health as a social product; it wrongly assumes the existence of free choice; and it is ineffective in preventing ill health" p72. She sees the future of the empowerment approach to health education, and indeed prenatal screening in the principle of self-empowerment advocated by Tones (1992), where voluntarism and modified authoritarianism can unite. Thus modified authoritarianism involves providing pregnant women with the information necessary to make informed choices, and voluntarism involves empowering women to make their desired choice as a result of the unbiased support received from the health educator. Indeed, there is no attempt to coerce or persuade the client.

The integration of health education, social and political themes is suggested by the World Health Organisation (1983, cited in Pike and Forster, 1995) definition of health promotion. This complements the model developed by Tannahill (Downie et al., 1990), which defines three overlapping spheres of activity: health education, health protection; and prevention. These activities inter-relate to produce an all-inclusive process termed health promotion. In

this model health education forms close links with the preventative sphere. Prenatal screening fits closely within this model because current government policy advocates that pregnant women should be given information to make informed choices regarding their care (Department of Health, 1993), thus implementing health education measures. The corresponding overlap with the preventative sphere is defined by the Department of Health (1993), which views the ethos of prenatal screening as reducing the number of mothers who would be faced with the task of caring for a child with special needs, and subsequently the demands on state services would be eased. How such an ideology affects our view of handicap and indeed affects the handicapped themselves will be discussed.

Bennett and Hodgson (1992) suggest that psychologists and health promoters must work together to develop theory and practice regarding health promotion. Probably the best known theoretical model highlighting the function of beliefs in decision making is the Health Belief Model (Becker, 1974). When considering an individual's readiness to consider his/her behaviour in relation to health, the health promoter must consider the value of health to that individual, when compared to other aspects of life; the person's perception of the seriousness of the health problem; the perceived implications of the health problem; and the belief in diagnosis and potential therapy. The health belief model focuses on the cost as well as the benefits of changing behaviour. It acknowledges that health promoters will have to cue actions to motivate or maintain behavioural change. Although the offer of prenatal screening does not require pregnant women to make any changes in their physical behaviour, it does require them to dedicate time and effort in the consideration of such tests. For this reason a change of attitude may be desired in the way prenatal screening is initially perceived, thus the health belief model may serve to guide the development of counselling techniques. Indeed people often need to pass through stages of changing attitudes and assimilating

information before they are able to make any changes in their behaviour (Anderson and Wilkie, 1992).

ATTEMPTING TO REMOVE HANDICAP FROM SOCIETY

Stacey (1988), points out that the ability to detect handicap and terminate a pregnancy does precipitate problems. Firstly, there exists a paradox in that increasing choices can remove other choices and impose restrictions. Rotham (1985) argues that the choice to avoid bearing a handicapped child can become a forced choice; that is, in gaining the choice to control the quality of our children, we may lose the choice of simply accepting them as they are. To support this view, Farrant (1985) reports that some women are allowed amniocentesis on the condition that they agree in advance to abort an affected pregnancy.

Secondly, Stacey (1988) states that there are consequences in changing normative expectations. Modern society is designed for the fit and well thus inflicting difficulties upon the handicapped and their parents. A handicapped person may be stigmatized because he or she does not have the required intellect or body image to fit into our striving society. She goes on to suggest that similarly a woman who decides to bear a handicapped baby (despite being given the choice of termination), may be condemned for failing to take that option and consequently inflicting the burden of handicap upon herself and society. As a result, the expectation that some children will be born handicapped has now changed to the expectation that women will be responsible for establishing the fitness of their baby before progressing with the pregnancy.

Thirdly, there are implications for the non-congenitally handicapped and those who are already living. Consideration should be given to their feelings regarding the resources allocated to removing people like them from future society (Stacey, 1988). Indeed, advanced gene therapy cannot exclude all handicap and some disabilities occur as a result of accident later in life. Concentrating on the removal of handicap will make it harder for the inevitable handicap to be accepted, not least by the handicapped themselves. The perception of mothers as vessels for the production of 'perfect children' will accentuate problems for those who still bear handicapped children (Stacey, 1988). Kaback (1983) discusses the psychosocial considerations such families must face, suggesting that the whole family can be affected by feelings of guilt and anxiety. Furthermore, unrealised hopes and ambitions of producing a healthy child can lead to stigmatisation and altered lifestyle. Borg and Lasker (1982) describe such parents feeling that they have failed to accomplish what every 'normal' couple seem able to achieve without difficulty. Moreover, women may feel that their bodies cannot be relied on, and that they may never produce a normal child, particularly if the affected child was the first. These arguments do not suggest that the efforts of geneticists are misplaced, but that attention should be paid to the social implications of their work. Indeed, although the biological base should be recognised as important, a humane and caring society considers that the social implications of any action are important; moreover one cannot be isolated from the other (Stacey, 1988).

CHAPTER TWO

LITERATURE REVIEW

In order to locate this study within the context of current understanding, critical examination of the literature was undertaken in two broad areas. They are, the psychological consequences of screening and the amount of information given to potential participants of screening, including the knowledge base possessed by health professionals responsible for counselling prior to screening being accepted or declined. In this way, it can be demonstrated where previous studies have highlighted problems, and subsequently formulated arguments for improvements to be made within the system, as well as illustrating why the current study is important and timely.

THE PSYCHOLOGICAL CONSEQUENCES OF SCREENING

The ability to detect fetal abnormality in utero, and the attendant offer of termination, raises issues for both the providers and users of such services. Marteau (1991) suggested that a psychological perspective could be used to answer two key questions which arise from the implementation of screening procedures: which factors influence test uptake? What are the effects of testing for those undergoing prenatal screening? Indeed the review of empirical studies throughout this section will serve to gain a critical understanding of these two areas. High levels of anxiety have been reported in patients participating in screening programmes (Marteau, 1989), and some patients have been more anxious following screening, despite receiving a normal result (Stoate, 1989). Marteau (1990) proposed that this anxiety could

be reduced if careful attention was paid to the patient's needs on the invitation to participate in the programme, the preparation of those who decide to undergo the test, and the giving of results. She subsequently suggests that staff themselves must receive comprehensive training if they are to attend to patient's needs, including not only knowledge of the test(s), but also in communication skills, so that information can be effectively presented and individual patients' needs and anxieties addressed. Bird and Lindley (1979) point out that many health professionals presume they already have the necessary skills, but evidence suggests that a brief training course would reap benefits. However, in 1992, Marteau and Slack observed that lack of attention to these requirements may suggest that uninformed decision making, raised anxiety and false reassurance are continuing to occur.

Stratham and Green (1993) report on the considerable problems encountered by women receiving positive test results, including the fact that all women were anxious following a positive result, no matter how they were informed. The study further highlighted the lack of knowledge possessed by the women regarding implications of test results and how health professionals were unprepared in dealing with patients who had received positive results. The authors do acknowledge that the study may not be a representative sample of those with positive results, since they were selected from those who had contacted 'Support After Termination for Abnormality' and thus may have been more anxious. However, positive results are known to generate anxiety (Green et al., 1993, Marteau et al., 1988) and a Dutch study did reflect similar results, suggesting that the problems encountered are widespread (Roelofsen et al., 1993).

In an earlier study Marteau et al. (1991) described the impact of false positive results, by comparing two groups of women; those receiving a negative result (n=346) and those

receiving an initial positive result (n=26), over four time points - prior to testing, immediately after testing, later in pregnancy, and in the post-partum period. Although the study population were randomly selected, the women who completed all questionnaires were significantly older, more likely to be born in the UK, of higher social class and had lower levels of pre-existing (trait) anxiety. This may affect the validity of the results because a high degree of motivation was required by participants to qualify for completion of all questionnaires and subsequent analysis of data. The results correlate with the later studies outlined above, in that receipt of a positive result is associated with high levels of distress. The study illustrated that this resulted in increased worry about the baby's health and a more negative attitude towards both the baby and the pregnancy. The study also found that negative results from further diagnostic tests, following an initial positive result, do not necessarily provide reassurance, indeed anxiety levels remained high for many women. However, Burton et al. (1985) refutes this trend, although the reliability of the measures of attitudes to pregnancy in this study are questioned (Marteau et al., 1991).

Studies conducted to date illustrate that pregnant women are suffering considerable anxiety as a direct result of prenatal screening, and those who receive a negative result remain unaware of the potential implications. Indeed there is evidence to explicitly link the receipt of both positive and false positive results with raised levels of anxiety and distress. Clarke et al. (1993) conclude that the current system of implementing prenatal screening appears to pay little attention to the social and psychological requirements of those who are offered screening. It is important to make the point that despite the use of advancing technology, screening tests do not detect all cases of fetal abnormality. Therefore some women will give birth to an affected child despite receiving a negative result following testing. However, it is interesting to note that there have been no studies to date which have investigated how

receiving a false negative result can affect the adjustment of both the women and their families to the birth of a handicapped baby.

WHAT INFORMATION IS GIVEN TO WOMEN ABOUT PRENATAL SCREENING?

Marteau (1991) points out that two main factors will bear an influence upon whether pregnant women accept prenatal screening. These are the knowledge and attitudes of the health professionals who offer such tests, and the knowledge and attitudes of the women themselves. Presenting screening tests to a healthy population demands a change of role for both the health professional (from a curative to a preventative approach), and patients (from a passive to an active role). It also confronts health professionals with the problem of informing clients about the low probability of serious events, without reassuring them falsely or unduly alarming them.

It is documented that people's understanding of screening tests for which they are eligible is frequently poor (Marteau et al., 1992). A study by Marteau et al. (1992) aimed to determine if this was due to the way the test was offered and explained. One hundred and two consultations between midwives and obstetricians and pregnant women were tape recorded. Although the study population was of mixed parity and social class, the sample and each consultation was opportunistic and not random. Furthermore, it could be argued that tape recording the interview may have changed each subject's behaviour, although Redman (1989), proposed that individuals' behaviour remained unchanged under such circumstances. The authors concluded that in almost all consultations, the screening test (maternal serum AFP) was introduced by health professionals, but little information was given about the test, the conditions it screened for, or the meaning of either positive or

negative results. The way the test was presented was biased in favour of encouraging test uptake, with patient choice or the limitations of the test not being emphasised. However, practical details of when to attend were given. These results accord with those from a survey of consultant obstetricians by Farrant in 1985, which highlighted the fact that twenty-five percent of consultant obstetricians acknowledged and admitted to making no active efforts in facilitating the client's understanding of the implications of testing.

In addition, one reason for poor knowledge regarding prenatal screening tests was the fact that little information is given to potential participants. Marteau et al. (1992) also found that those who accepted screening were more knowledgeable than those who declined, perhaps because giving more information about the test swayed them towards acceptance, or that they elicited more information from the health professional because they intended to have the test. Furthermore, Smith et al. (1994) also found that women lacked knowledge about aspects of the tests that could inform their decision on whether to accept or decline screening. Smith et al. (1994) stress that understanding the implications of screening may have helped to prepare clients for the event of being recalled with a positive result, or for the event of giving birth to an affected child following receipt of a low risk result. A later study by Sullivan (1995) concluded that although many women understood that they can have further investigations if they are shown to be high risk, they do not fully appreciate the full range of options available to them and the potential risks that this incurs. Indeed, Marteau (1992) proposes that this lack of understanding may result from health professionals failing to give pregnant women the necessary information.

A study by Smith & Marteau (1995) compared the amount of information given to women about scans for fetal abnormality to that given regarding serum screening tests. Two hundred

and fifteen consultations between pregnant women and midwives or obstetricians were tape recorded in six UK hospitals. Chi-square analysis concluded that information regarding serum screening was given significantly more frequently than information about fetal anomaly scanning, indeed the topic of fetal anomaly scans was omitted altogether in over a third of consultations. The information given related to the more practical aspects of the tests, failing again to address the implications of testing, including positive and negative results. The authors felt that the relative paucity of information given about ultra sound scan could be attributed to the health professionals perception of scanning. It is a physically non-invasive procedure, involving little physical discomfort and is considered to offer pregnant women the positive psychological experience of seeing an image of their baby. Furthermore, there may be a belief that the ultrasonographer will give information at the time of scanning. However, Smith & Marteau (1995) stress that such information should be given to the client prior to attending her appointment, if she is to be enabled to make an informed choice, and to feel free and comfortable in making her choice.

In a further study by Proud and Murphy-Black in 1995, a questionnaire was sent to a stratified sample of one hundred maternity units, of which ninety-four responded. The findings of Smith & Marteau (1995) were echoed, in that a minority of units gave comprehensive, unbiased information to facilitate informed decision making regarding ultrasound scan. Specifically 24% of units imparted no information at all; 28% of units supplied information about the procedure itself and how the woman should physically prepare herself, and 48% of units imparted information that included some indication of the scan's potential to detect fetal abnormality. Indeed in eight units, women who declined scanning because they did not wish to know about any potential fetal abnormality, were actively persuaded to have a scan for other reasons, despite the fact that major abnormalities could

not fail to be noticed. A review of the literature suggests that the knowledge base of pregnant women regarding prenatal screening is limited because health professionals are failing to provide clients with the necessary information to facilitate understanding of screening and its implications. In this way clients are therefore unable to make fully informed decisions regarding test uptake.

WHY DO HEALTH PROFESSIONALS FAIL TO CONVEY THE REQUIRED INFORMATION?

Lack of knowledge about screening tests for fetal abnormality among midwives and obstetricians has been found to be a barrier to giving information to women (Smith et al., 1994b). Twenty-one obstetricians and seventy midwives completed a multiple choice questionnaire regarding knowledge of prenatal tests, reluctance to disclose uncertainty, and clinical experience. 43% of midwives and 14% of obstetricians obtained correct responses on fewer than half the items regarding knowledge of the tests. However, the authors do caution that the obstetricians may be more experienced than the midwives in completing multiple choice questionnaires, thus partly explaining their higher scores.

The less knowledgeable obstetricians were more reluctant to disclose information to patients, whereas the midwives with more clinical experience were less likely to disclose information to patients. Thus, reluctance to disclose uncertainty to patients was associated in obstetricians with having less knowledge about prenatal testing; and in midwives, with more clinical experience. The authors propose that the obstetricians with less knowledge, subsequently lacked confidence in their ability to disclose uncertainty and therefore avoided such discussion. Conversely, for midwives, it was the greater clinically experienced

individuals who were reluctant to disclose uncertainty, and the authors suggest several possible reasons for this. Firstly, the more experienced midwives may feel more assertive in admitting their reluctance to disclose information, even though it is against clinical guidelines. Secondly, different philosophies may have dominated the training of both the more and less experienced midwives; and subsequently the more experienced midwives who have practised longer may have had a negative experience of admitting uncertainty. A further possible explanation is that the years since qualifying may not equal clinical experience because some midwives may have had career breaks or worked part time. One could also speculate that the more recently qualified midwives are more likely to have received a more liberal training regarding patient choice and autonomy. Indeed lack of knowledge on the midwives' behalf is similar to that reported in an earlier Swedish study (Sanden, 1985), reflecting the absence of formal education for health professionals when new tests are introduced. Recognising this problem, the Royal College of Obstetricians and Gynaecologists recommended that a specialist member of staff should be designated as being responsible for the implementation of prenatal screening (RCOG, 1993).

A study by Fairgrieve et al. (1996) evaluated the impact of introducing a team approach to maternal serum screening. A screening co-ordinator was appointed to set standards in the delivery of service, based upon a *'gold standard'* defined by Burn in 1996. Each co-ordinator was responsible for data collection, production of annual reports (thus facilitating ongoing monitoring and evaluation of the programme), and the continuing education and support for midwives and other health professional involved in prenatal screening. The study concluded that this team approach is a helpful basis for the efficient delivery of maternal serum screening service, but that the role of the co-ordinator was not recognised as a link between theory and practice by some managers and other disciplines. The need to provide

staff with effective training to increase their knowledge about screening tests and to impart complex information using effective communication skills is of paramount importance. A study by Smith et al. (1995) suggested that when midwives and obstetricians were subject to a very brief training programme, together with individual feedback on their performance, significantly more information using effective communication skills was imparted to patients.

Other factors which will have an influence upon the delivery of information to clients are staff beliefs about the importance of information to decision making, and their attitudes towards imparting such information to patients. Proud et al. (1995) found that some midwives actively withheld information from patients - perhaps this is a case of midwife versus women's autonomy. Whilst they were willing to answer questions, the midwives did not volunteer any further information. Such an attitude is condemned by Beech (1992) because it leads to ownership of information, ensuring that power and control remains with the health professional, thus depriving the patient of personal autonomy, which is necessary for informed decision making. Furthermore, some midwives voiced concerns that the women would not understand the issues involved and that any discussion would merely serve to raise patient anxiety. Therefore it was considered inappropriate to disclose information about fetal abnormality, as this would not be in the patient's best interests. However, autonomous decision making is not possible when staff presume that they have a right to decide what information the clients require. Marteau (1993), challenged this utilitarian approach of paternalistic practice and suggests that inadequate information raises anxiety levels, in fact patients actively seek and desire such information (Ley, 1988). A further reason for withholding information was reported to be that it may discourage the women from participating in screening programmes (Smith & Marteau, 1995; Proud et al., 1995), and this is undesirable because the data is required by health professionals to monitor the

progress of the pregnancy.

Khalid et al. (1994) points out that an increasing part of midwives' workload is involved with supporting patients who have to make difficult and complex decisions as a result of prenatal screening. The study of three hundred and forty-two midwives by Khalid et al. (1994) indicated that 40.4% of midwives did not feel confident counselling for maternal serum screening; 38.3% felt that termination for Down's syndrome could not be justified; and 25% were not in favour of maternal serum screening. The authors conclude that the key group responsible for counselling feel unprepared for this role and experience personal ethical dilemmas about screening. As a result they recommend that staff training should address both the factual requirements necessary to effectively counsel clients, as well as considering and respecting the personal views of the staff themselves. Smith et al. (1994) echoes this view in calling for future staff training to accommodate and understand the attitudes that underpin clinical practice of health professionals. In this way they are facilitated in presenting complex ethical dilemmas to clients, whilst leaving their own personal beliefs intact.

Khalid et al. (1994) proposed that the amount of time spent on presenting a screening test may be linked to the amount and quality of information given to the client. Only 39.4% of midwives felt they had adequate time to discuss these tests with women. However, Marteau et al. (1992) do not support the hypothesis that insufficient time available contributes to cursory presentations of screening, as the amount of information imparted to patients was unrelated to the duration of consultation. She does, however, state that lack of knowledge, poor communication skills and negative attitudes towards patients' information needs may be factors inducing a brief consultation. Moreover, they move on to propose that such

presentations can become habitual, that is, they are relatively invariant with little conscious attendance on behalf of the performer. Furthermore, the attitudes of women themselves may have an influence on how those tests are presented. They may be reluctant to overtly acknowledge a fear of fetal abnormality, feeling that staff should advise them on what to do, thus keeping discussion regarding prenatal screening to a minimum (Marteau et al., 1992).

The knowledge and attitudes of health professionals will in turn influence womens' knowledge and attitudes (Marteau, 1991). Surveys of womens' attitudes towards screening reveal that over 95% are in favour of such tests, although slightly fewer actually accept the tests on offer (Kyle, Cummins and Evans, 1988, cited in Marteau, 1991). Three key factors are identified by Marteau (1991) as determining whether women undergo screening. They are, the knowledge of the test; the attitude to termination; and the perceived risk of having an abnormal child. Indeed, the limited knowledge of pregnant women in relation to prenatal screening was previously cited by Marteau in 1990, who had linked the subsequent lack of understanding to raising the client's anxiety levels. Marteau et al. (1989) point out that those who undergo testing have more knowledge than those who do not. Furthermore, Marteau et al. (1991, cited in Marteau, 1991) propose that those opting out of testing may have truly intended to do so, as a direct result of informed decision making. However, there may be clients who decline testing because they lack the necessary information which could inform their decision.

Given our knowledge of the problems experienced regarding the implementation of screening tests, in recent years very little appears to have changed in an attempt to tackle them (Marteau, 1993). The failure of research findings to inform change in clinical practice is a recognised phenomenon and may be partly responsible for such a trend (Peckham, 1991).

Furthermore, health professionals may remain ignorant of the unmet needs of patients who receive positive results because they often seek support and advice from independent agencies such as the Down's Syndrome Association (Marteau, 1993).

Marteau (1990) points out that more people are now being screened for more conditions over greater spans of their lives as a result of advancing technology, increasing expenditure on health and the recent introduction of financial incentives for general practitioners to carry out some forms of screening. Whelton (1990) states that the screening of pregnant women for potential fetal abnormality has become routine. Indeed Proud (1995) stresses that the technology has been developed and introduced at such a rapid rate that it is now difficult to imagine implementing antenatal care without it. Enkin and Chalmers (1982, cited in Marteau, 1991) suggested that improvements in pregnancy outcome have encouraged expectations to rise faster than achievements. They state that antenatal care is now characterized by complex and invasive screening procedures, which reflect the unwillingness of doctors and patients to tolerate uncertainty.

Marteau (1991) felt that the high and increasing uptake of prenatal tests is due to increasing test availability, positive attitudes of obstetricians and midwives regarding the use of such tests, and the increasing demand and acceptance for such tests from pregnant women. However, Marteau (1990) does caution that the way an effective screening test is offered will influence how much good or harm it offers. She stresses that the roots of adverse psychological consequences of screening stem from the fact that people do not understand what the test is for, its accuracy and the potential implications of test results. Therefore accurate and detailed information about these tests must be given to clients if they are to be active and informed participants in decision making regarding test uptake (Marteau, 1991).

This chapter has revealed that previous study indicates that pregnant women are unable to make informed choices regarding prenatal screening because their knowledge base is limited. Foster (1995) voices her concern in relation to this and describes an "obsession" with screening which has evolved from the powerful advances of technology, resulting in a belief that control and technological advances are desirable ways forward for health care. She advocates keeping the advantages of screening in perspective by maintaining scepticism towards such tests. Furthermore, Marteau (1993) who has extensively researched the implementation of screening procedures, proposed that the future improvement of screening services rests with the purchaser - provider relationship which underpins current health care provision. In this way, contracts for prenatal screening services could explicitly require evidence and assurance that clinical teams are trained to provide information and emotional support for clients at all stages of screening and diagnosis.

CHAPTER THREE

METHODOLOGY

There are two different levels in the process of generating knowledge; methodology which refers to the knowledge producer's overall strategy, and the method, which relates to the specific tools used to achieve this task. To set this within the context of the current study, the overall strategy is to investigate how much pregnant women know about prenatal screening, and then to subject the data to statistical analysis in order to further define the current knowledge base. The chosen method involves collecting data using a cross-sectional survey, where participants are asked closed questions about certain aspects of their knowledge.

An understanding of how the instruments used by researchers work and the kinds of knowledge they produce is only part of the problem. It is equally important to know why they are used, thus defining the purpose of the researcher. Although it is important to know what a certain method is technically capable of doing, it is imperative to understand what particular task it is required to perform, because the same research method may be used for very different ends. Moreover, as Jones (1993) points out that there is little inherent quality in a research tool, indeed the uses to which the researcher chooses to put it are of more importance. In order to understand the use of data collection techniques, there must be an appreciation of the context in which they are employed, which is revealed by understanding the ontological and the epistemological orientation of the researcher. Jones (1993) points out that the production of knowledge by human beings is dependent upon the researcher's ontology, that is, their definition of subject matter or their perception of reality.

Epistemology refers to what the researcher counts as knowledge and the nature of the knowledge sought will often determine the methodology and methods employed to acquire it.

The use of structured interviews is considered by the researcher, to be a more accurate way of measuring the knowledge base of pregnant women when compared with earlier observational studies where counselling sessions were observed or recorded. This is because it acknowledges that the knowledge base of clients is not solely based upon the information given by health professionals, but is also influenced by external factors such as the media and the experiences and views of family or friends. Thus we are able to reveal a more accurate picture of what pregnant women actually know in accordance with how they interpret the information they have received. Although the subjective nature of this data is set within an anti-positivist paradigm, it was felt that the first step in the process of defining the problems encountered in the implementation of prenatal screening, was to provide demonstrable proof that the knowledge base of clients was inadequate, if informed consent is to be given. Thus, the positivist approach of empirical enquiry would serve to collect evidence by counting the number of times clients were in possession of certain key issues relating to screening. The subsequent quantification facilitated by the structured nature of the survey was followed by statistical analysis of these data, in order to discover any significant relationships. The multi-variate analysis of each participant's knowledge base with certain demographic factors (age, social class, parity, place of booking), enabled the researcher to propose possible explanations for the distribution of knowledge.

In effect, Jones (1993) states that positivism declares that a claim to knowledge must solely rest on what can be shown to be the case in an objective fashion, thereby excluding

subjective factors such as opinions or preferences. The key epistemological question which must be addressed is how can a researcher justify what he or she defines as knowledge. To set this within the context of the current study, the epistemological orientation remains centred upon working within a positivist paradigm. As far as possible, the information base possessed by pregnant women is objectively gauged, using a structured research tool. The researchers knowledge emerges from a systematic assessment of the information that the client is able to articulate at the point of contact with the researcher. Although every attempt was made to be objective, each interview involves the researcher and the interviewee and within the limitations of human behaviour, it is not possible to be completely objective. Thus, the current study aims to assess the knowledge base of pregnant women which results from the information revealed to them by external factors such as health professionals, the media, family or friends. Indeed the epistemological orientation of the positivist insists that only demonstrable empirical proof of the explanations of reality is acceptable and such ideology is deemed appropriate as the first step in the process of establishing the knowledge base of pregnant women in relation to prenatal screening and in enabling the researcher to identify the implications for service provision.

The desire not to influence or interpret the results should be stressed, and the interviewer made every effort to remain as objective as possible in relation to the subjective nature of the data. However, it is acknowledged that as a human being, a midwife and a mother, the interviewer can potentially instill a degree of personal bias upon the interpretation of the material and design of the data. Therefore it is possible to speculate that complete objectivity may not be possible. For the positivist researcher the problem of how to retain objectivity so that truth about structural forces can be acquired, must be further considered in relation to the interview itself. It must be acknowledged that as a result of being interviewed, there

may be a degree of anxiety felt by the participants because of the hospital setting and the interface with a health professional. Such anxiety may impose limitations upon the validity of the data because the participant may be in possession of the knowledge, but might feel inhibited in articulating her knowledge.

A QUANTITATIVE OR QUALITATIVE APPROACH?

Polit and Hungler (1993) make a distinction between the two broad approaches to gathering information. Firstly, quantitative research generally involves the systematic collection of numeric information and the subsequent statistical analysis of the resulting data. Secondly, qualitative research involves the systematic collection and analysis of more subjective narrative materials which enables researchers to explore the dynamic, holistic and individual aspects of the human experience. Polit and Hungler (1993) state that the selection of an appropriate method may depend upon the researcher's personal taste and philosophy, but it also largely depends upon the nature of the research question. As a general rule quantitative research tends to emphasise deductive reasoning, the rules of logic, and the measurable attributes of the human experience, and is therefore sometimes referred to as 'hard science'.

When considering the design of the study, there was a choice between working within an anti-positivist paradigm by using a qualitative approach and a smaller sample, or working within a positivist paradigm and utilising a quantitative approach and a larger sample. However, the study is to remain focused upon the measurement of specific levels of knowledge regarding the key issues of prenatal screening. Thus it was decided to opt for the largest possible sample facilitated by a quantitative approach. It was felt that the greater

number of responses would more accurately reflect the current knowledge status of the pregnant population. Furthermore, because the nature of the research question was to measure the levels of specific knowledge in relation to prenatal screening, it was decided that a quantitative approach would be effective in facilitating the collection and statistical analysis of numerical data. A quantitative approach and the use of closed ended questions effectively isolated the aim of the current study into solely measuring the levels of specific knowledge because participants were not able to respond in an elaborate way. However, this was intentional and it was acknowledged that the analysis of qualitative data within the same study would exceed the available resources.

Should the current study illustrate that pregnant women possess limited levels of knowledge in relation to prenatal screening, then it is intended to design and implement future studies to further define the nature of the problem. An anti-positivist approach producing qualitative data would be invaluable for future study, which would aim to capture a holistic picture of the experiences and opinions of women who are offered screening. Such an approach would facilitate the exploration of the social and psychological effects of offering pregnant women the choice of establishing the normality or otherwise of their unborn baby. It was recognised that the use of a quantitative approach imposed limitations upon the study because information regarding the complete experience of screening was not accessed. However, it was decided to effectively address the research question in the current study by initially using a quantitative approach, and subsequently reserving the use of a qualitative approach to inform future studies.

The Research Tool

On initial examination it was felt that a questionnaire completed independently by the study population would be an appropriate tool, because a large number of respondents could be accessed without using the expensive time of an interviewer. However, as a direct result of the pilot study, it became apparent that certain questions were very difficult to phrase without necessitating clarification. Therefore, I felt that it would enhance the validity of the data if I used the questionnaire as my guide for a structured interview, enabling each participant to receive clarification on the complex issues. Furthermore, the use of structured interviews involving direct contact with the research midwife ensured that the study was interactive and not extractive. In this way, each participant was given information regarding screening, which would help to clarify her understanding of the issues that were pertinent to them. Moreover, on completion of each interview, the emotional and psychological well being of each individual was considered, by giving every participant the opportunity to discuss any uncertainties or anxieties that they had experienced as a result of screening, or as a result of being involved with the study. Indeed, it could be suggested that although the study method was quantitative, the form of the interviews were of a qualitative nature, because certain issues arose during conversation that did not relate directly to the study, thus a less structured approach to the interview did evolve, although the central purpose of each interview remained the collection of specific data. However, the interviewer did acknowledge and respond to these issues and concerns that had spontaneously arisen.

Barker (1991) warns that the quality of information generated from interviews is dependant to a great extent on the behaviour of the interviewer. Indeed Rees (1995) stresses the need to acquire interview skills and practice these skills before implementing the study. Rees

(1995) also states that respondents who are being interviewed may be more inclined to provide 'socially acceptable' answers, or may feel that they are being put on the spot or 'tested'. The pilot study illustrated that due to the large number of questions within the structure of each interview, there was a need to avoid bombarding each respondent with repeated questions, as this would potentially make the interviewee feel uncomfortable, or as if they were being 'tested'. Indeed the technique of gently and informally presenting questions to participants was practised and refined on colleagues and during the pilot study. Furthermore, the interviewer made every attempt to ensure an informal setting, by not wearing a uniform, but an identification badge stating a midwife status. The interview room contained soft chairs, set comfortably apart at equal heights, with no table in between, thus optimising the chances of comfortable conversation taking place. Finally, each interview required considerable time and thought to set up and be implemented, thus reducing the sample size that might otherwise have been achieved if a self completing questionnaire had been employed. However, it was felt that this was off-set by the enhanced quality of the data obtained.

Rees (1995) cites further advantages of using interviews as a tool for research. The response rate is usually high - indeed only three potential participants refused the invitation to take part in this study. Two voluntarily disclosed a time factor problem due to other commitments, and another exercised her right to give no explanation. Furthermore, most of the data are usable and immediately available to the researcher.

The autonomy of pregnant women and its implications for informed consent and service provision remain central to this study, and for this reason the questions selected for the guidelines of the interview were carefully crafted to ensure that the research question could

be properly addressed. It was not assumed that as researchers and health professionals, we have the right or knowledge to define what pregnant women want or need to know in order to make informed choices regarding prenatal screening. It was acknowledged that it is wise to utilize knowledge and instruments employed by other credible studies, which had previously identified which key elements of knowledge were relevant and important. In this way, the questions within each interview were closely linked with those used in an observational study by Smith and Marteau in 1995, where information imparted by midwives and obstetricians during consultation with pregnant women was analysed. Furthermore the questions regarding knowledge of screening tests were also devised from recommendations set out by the Royal College of Obstetricians and Gynaecologists in 1993.

CONTENT OF STRUCTURED INTERVIEW

The prefix of (I) or (P) denotes which aspects of knowledge were defined by the researcher and Smith & Marteau (1995), as the practical aspects of screening (P) and the implications of screening (I).

i) Information requested regarding specific knowledge of key issues relating to <u>both</u> maternal serum screening and ultrasound scan was as follows:-

(I) - The possibility of receiving false positive results.

(I) - The possibility of receiving false negative results.

(I) - The possibility of having to discuss and consider termination of pregnancy.

(P) - The fact that each test was optional.

ii) Information requested regarding specific knowledge of key issues relating to maternal serum screening was as follows:-

(P) - The test is not able to <u>diagnose</u> Down's syndrome, only to screen for this condition.

(I) - Amniocentesis is offered to actually <u>diagnose</u> Down's syndrome in the event of a positive result.

(P) - Amniocentesis incurs a one percent miscarriage risk.

(P) - The results of amniocentesis can take up to four weeks.

iii) Information requested regarding specific knowledge of key issues relating to ultrasound scan was as follows:-

(P) - The procedure cannot screen for ALL abnormalities.

(P) - The main purpose of having a scan was:

- screening for fetal abnormality; or
- being able to see the baby.

iv) Information requested regarding the practical aspects of how maternal serum screening and ultrasound scan were offered which may bear an influence on decision making. The following questions were asked in relation to both maternal serum screening and ultrasound scan as follows:-

- Was the test offered in the first place?
- Was this offer accepted?
- Was the test explained by a health professional?
- Was a written information leaflet given?

v) Information requested relating collectively to maternal serum screening and ultrasound scan was as follows:-

- Did the respondent discuss the test with her partner?
- With the information given, did the respondent feel confident making the decision?
- Who gave the most useful and understandable information? (the midwife, doctor, family/friends or media).

A full copy of the guidelines which served to define what data was collected at each interview is placed in the appendices.

The Study Sample

The study sample comprised two hundred pregnant women who were interviewed over an eight week period during March and April, 1996. Prenatal screening is usually offered to clients by the midwife during the initial booking interview at eight to twelve weeks, when discussion regarding the screening tests offered and their implications may take place. However, the blood sample for maternal serum screening is not taken for analysis until fifteen to nineteen weeks gestation, and ultrasound scanning is not performed until eighteen to twenty weeks gestation.

All participants were invited for interview whilst they were attending the antenatal clinic for an ultrasound scan at twenty weeks gestation, because it was considered that the experiences and issues underpinning their decisions regarding prenatal screening would still be fresh in each participant's mind at this point.

Every woman who books for antenatal care at Chester is invited to the hospital at twenty weeks gestation so that her obstetrician can review and plan care for the remainder of the pregnancy following her ultrasound scan. However, for many reasons, there are a small number of clients who do not attend for this appointment. They may simply have forgotten or may have failed to receive an appointment through administrative error. Some individuals may actively choose not to participate in a proportion or all of the antenatal care offered to

them. These individuals were not involved in the study. Indeed although the numbers of participants who fell into this category were small, this did not represent a limitation of this study.

The study took place in the Spring of 1996, as this was a convenient time for the research midwife to be allocated time to implement the study. It was envisaged that no bias would have occurred from this timing, as no individual factor could influence when and who became pregnant during the time allocated to the study. However, it was acknowledged that other external factors may have had an influence upon the participant's knowledge and perception of prenatal screening. In particular, at the end of January 1996 a documentary was televised which investigated and explored the experiences of pregnant women who underwent maternal serum screening. Similarly, other media publications may have been available to the study population, or there may have been involvement with the experiences of a family member or friend in relation to prenatal screening.

Rees (1995) makes the point that interviewing a study population is more time consuming than using questionnaires which can be completed independently by the participant. However, notwithstanding the advantages of independently completed questionnaires, it was felt that there were specific advantages of the interview method that outweighed these. Specifically there were questions relating to the potential for false positive and false negative results and it was envisaged that the interviewer could ensure that the participants fully understood the meaning of such terms. Indeed participants would be able to seek clarification from the interviewer in relation to any of the questions posed, thus maximising the opportunity to collect accurate data. It was acknowledged that the largest possible sample would enhance the validity of the study because of the higher number of individual responses

that would be available for analysis. Within the limitations of time and resources available, it was decided that subjects would be invited to participate in the study, until two hundred interviews had been completed. Furthermore during February 1996, a pilot study of twenty participants was carried out in order to test the design of the study.

Other than those individuals who declined the invitation to participate in the study, there was one group who were excluded. These were individuals within the study population who had received information which indicated that their baby was, or might be affected by fetal abnormality, as it was felt that being involved in the study may further their anxiety at what was already, a very difficult time. Furthermore, as a result of receiving a positive result, it was envisaged that these individuals may have actively sought further detailed information regarding the screening test involved, from either health professionals or appropriate support groups. Therefore, these people might have been in possession of an atypical knowledge base regarding certain aspects of screening. It was felt that this may have affected the validity of the results and hence provided further justification for their exclusion from the study.

The procedure used to implement the interview

Following approval of the study by the local ethics committee, the pilot study was carried out to test the study design. Originally it had been proposed to select the study population by inviting women from alternate appointment times, thus ensuring even spacing and adequate time for each interview. However, the pilot study indicated that it would be possible to select all individuals attending for a twenty week gestation appointment, as described earlier. As a result of the pilot study, the interview room was changed, the

original being too noisy and lacking privacy. Although the content of the guidelines for interview were not changed following the pilot study, it did serve to bring to light which questions required clarification on the participants' behalf. Specifically participants had difficulties in appreciating that the purpose of screening was to identify a high risk population, whereas a diagnostic test identifies those with definite fetal abnormality. Furthermore, there were individuals who did not understand the meaning of a false positive and a false negative result in relation to both maternal serum screening and ultrasound scan. In order to maintain continuity and avoid bias, every participant received clarification on these issues, even if they appreciated or claimed to understand them.

On arrival at the antenatal clinic reception, the study population were given a typed and personally signed information sheet. This explained the nature and purpose of the study, specifying that the results would be used to help improve pre-test counselling procedures in the future. It emphasized that all the information collected at interview would be completely anonymous and treated as strictly confidential. It was also made clear that participation in the study was entirely voluntary and that a potential participant can decline or withdraw from the study without giving reason, and that such action would not affect their future care. Every attempt was made to communicate this information in a clear, understandable format. The information sheet was kept concise because although more detailed literature would have been very informative, it was felt that potential participants may not be in a position to devote the necessary time and attention to read a longer document. Each potential participant was given time to read the information sheet and duly consider her decision on whether or not to participate in the study. Anyone requiring further information regarding the study was given this by the research midwife as necessary.

The information sheet did specify that each interview would take approximately ten to thirty minutes to complete, therefore this factor could be accounted for when deciding whether or not to participate. However, in reality, there was generally ample time to interview each participant whilst she was waiting to see the obstetrician. In these cases, each participant was informed and assured that she would not lose her place in the schedule of appointments to see the doctor. Having obtained verbal consent to take part in the study from the woman, the research midwife escorted the participant to a private, quiet room where written consent was gained. (Copies of both the information sheet and consent form which were given to each participant prior to interview are available in the appendices). It should be pointed out that further clarification regarding the study and subsequent verbal consent was secured before the participant was taken to the room for interview. In this way it was felt that individuals would feel less inhibited, should they wish to decline the invitation for interview. Any individuals who did decline the invitation were politely thanked for considering to take part in the study, and left to continue their visit undisturbed.

Following implementation of the structured interview as described earlier, each participant was asked by the research midwife if she was unsure or unhappy about any aspect of her care in relation to prenatal screening, either as a direct result of interview or if this situation existed prior to coming to the clinic. If it became apparent that any participant required further advice or assistance, then this was duly sought from the appropriate health professional. Each participant had previously been given the name of the research midwife and the telephone number of the antenatal clinic, therefore should any queries arise at a later date, contact could easily be made with the appropriate health professional. It was hoped that the design of the study and the procedure was such that each individual was able to exercise her right to autonomy in making informed decisions regarding participation in the

study. Furthermore, each questionnaire was numbered and not named, therefore respecting anonymity and the data was stored in a locked cupboard to ensure safety and confidentiality. In this way, it was hoped that participants were protected from any potential harmful effects of being involved with the study.

Data Analysis

In order to produce valid and reliable results, the way in which data was to be gathered and analysed was of prime consideration throughout the study. Data needed to be handled consistently, thus consideration was given to this fact when planning the question design that was to be used during the structured interviews, specifically bearing in mind that more structured questions are generally easier to analyse (Polit and Hungler, 1989). The expertise and support of a statistician was sought from the outset, who gave advice regarding the sample size, coding, collecting and analysing of data, including the use of a suitable statistical package.

The data were coded into four categories:-

i) Knowledge relating to both maternal serum screening and ultrasound scan.

ii) Specific knowledge relating to maternal serum screening.

iii) Specific knowledge relating to ultrasound scan.

iv) The practical aspects of how maternal serum screening and ultrasound scan were offered, which may bear an influence upon the decision making process.

Data from all four categories were used to produce descriptive statistics (in this case percentages), in order to facilitate effective summary of the results. These data were handled manually. Thereafter, data from the first three categories were combined to give each participant two overall 'scores' in relation to her specific knowledge regarding maternal serum screening and ultrasound scan. These scores are described as the total knowledge of key issues relating to maternal serum screening, and the total knowledge of key issues relating to ultrasound scan. This data was then processed using Minitab software and analysed to ascertain if there was any relationship with the following factors:

a) age

b) social class

c) parity

d) place of booking.

In this way it could be established if there was any statistically significant difference in the level of knowledge regarding both ultrasound scan and maternal screening within these four groupings. Analysis of variance and a pooled 'T' test were performed on the 'score' of knowledge in relation to maternal serum screening and ultrasound scan, both being considered separately. Following consultation with the statistician, it was decided that an analysis of variance would be the most appropriate statistical test to perform in order to assess if there was a statistically significant difference in the level of knowledge within the age and social class groups. This was because the variables of age and social class were divided into more than two categories as follows:-

a) Age
- less than twenty years
- twenty-one to thirty years
- thirty-one years and over

b) Social Group
- professional
- skilled
- semi-skilled
- unskilled
- unemployed
- "housewives"

The variables of parity and place of booking were divided into two categories as follows:-

c) Parity
- primigravida (first baby)
- multigravida (second or more)

d) Place of Booking
- hospital
- community

Following consultation with the statistician, it was decided that a pooled 'T' test would be the most appropriate test to assess if there was a significant difference in the levels of knowledge within the parity and place of booking groups.

The total scores obtained by each participant in relation to her knowledge of maternal serum screening and ultrasound scan were analysed using a paired 'T' test in order to establish if pregnant women were significantly more knowledgeable regarding either test.

Two tables were drawn up in order to illustrate and compare the distribution of knowledge in relation to the awareness of key issues underpinning the practical aspects and the implications of screening. The sub-divided scores obtained in relation to maternal serum screening and ultrasound scan were considered separately, and a chi-square analysis was performed to ascertain if participants were better informed in relation to either the practical aspects or the implications of both tests.

Finally, participants were asked if the midwife, doctor, media or family and friends had provided the most useful and helpful information regarding screening and these data were compared with each individual's total score in relation to the key issues of both maternal serum screening and ultrasound scan, using a one-way analysis of variance. Furthermore, the sub-divided scores obtained from both tests in relation to the practical aspects and the implications of screening were also subject to a one-way analysis of variance. In this way, it could be established if the source of information had influenced any aspect of knowledge in relation to both tests. Further data were also collected regarding the practical aspects of how each test was offered. It was felt that this information would help to inform the design of any amendments in the way prenatal screening is offered.

Limitations of the Study

Rees (1994) makes the point that a perfect or definitive research project is rare, indeed seldom does the researcher have perfect control over the conditions under which the data is collected. As a result of the pilot study it became apparent that there was a minority of individuals who did not have a husband or partner. In order to overcome this factor when defining social class, rather than excluding these participants from the study, it was decided to allocate the social class of each pregnant woman by her own occupation, rather than that of her husband or partner. On the one hand, it is useful to know the occupation of each woman because it more clearly defines her own social standing, rather than that of her husband or partner. Indeed this was considered quite appropriate in view of the fact that the study was measuring the level of knowledge possessed by the women themselves and not that of their husbands or partners. However, on the other hand, such a method does not accurately indicate the financial income of each household, although with the rising occupational status of women (Hallett, 1996), it could be argued that the traditional method of defining social class by the male's occupation also fails to indicate the total income of the household.

Amongst the study population there were individuals who actively chose not to work, therefore it was not appropriate to define these people as unemployed; rather they were classified under the heading "housewives". However, data was not collected as to their previous occupation (if any), and therefore it is not possible to make generalisations regarding their levels of knowledge in relation to prenatal screening. Indeed, if I was to design such a study again, I would endeavour to seek the previous occupations of the "housewives" because it would define their social class.

Furthermore, there are certain factors such as the influence of the media and the experiences or attitudes of family or friends, which will bear an influence upon the knowledge of pregnant women regarding screening. Evidently, these factors are not within the control of the researcher, indeed it could be argued that they may not impose limitations upon the validity of this particular study, because they reflect the social situations that exist within the context of everyday life. Moreover, as previously outlined, unlike earlier studies, the current study aimed to assess the knowledge base of pregnant women, irrespective of where they had obtained their information. In this way it was envisaged that any improvements located within the health service in pre-test counselling, would reflect the true social context within which we live, rather than merely considering what information was imparted by the health professional.

Despite the fact that every effort was made to ensure the comfort of all participants, by removing them from the familiarity of their own homes, into a hospital setting, and the subsequent interface with a health professional, an individual and varying degree of anxiety may be inevitable. Such anxiety may impose limitations upon the study because participants may possess the knowledge, but are not able to fully articulate what they want to say.

A further limitation of the study method may rest with the fact that non attenders were not followed up. Although there were only four such cases, the failure to capture the knowledge of these individuals may contravene the credibility of the study sample and indeed the results. In future studies, I will attempt to dedicate time and resources into the follow up of these individuals, so that they may be given the opportunity to take part in the study or to decline if they so wish.

CHAPTER FOUR

RESULTS

The sample consisted of a cohort of two hundred pregnant women who were interviewed regarding their knowledge of maternal serum screening and ultrasound scan. The distribution of participants within the cohort in terms of age, parity, social class and place of booking were as follows:

Table 1 : Distribution of age and parity.

Age in Years	Number of Primigravida (%)	Number of Multigravida (%)	Total (%)
Less than 20	13 (13)	1 (1)	14 (7)
21 - 30	54 (55)	48 (47)	102 (51)
31 and over	31 (32)	53 (52)	84 (42)
Total	98	102	200

Table 2 : Distribution of Age and Social Class

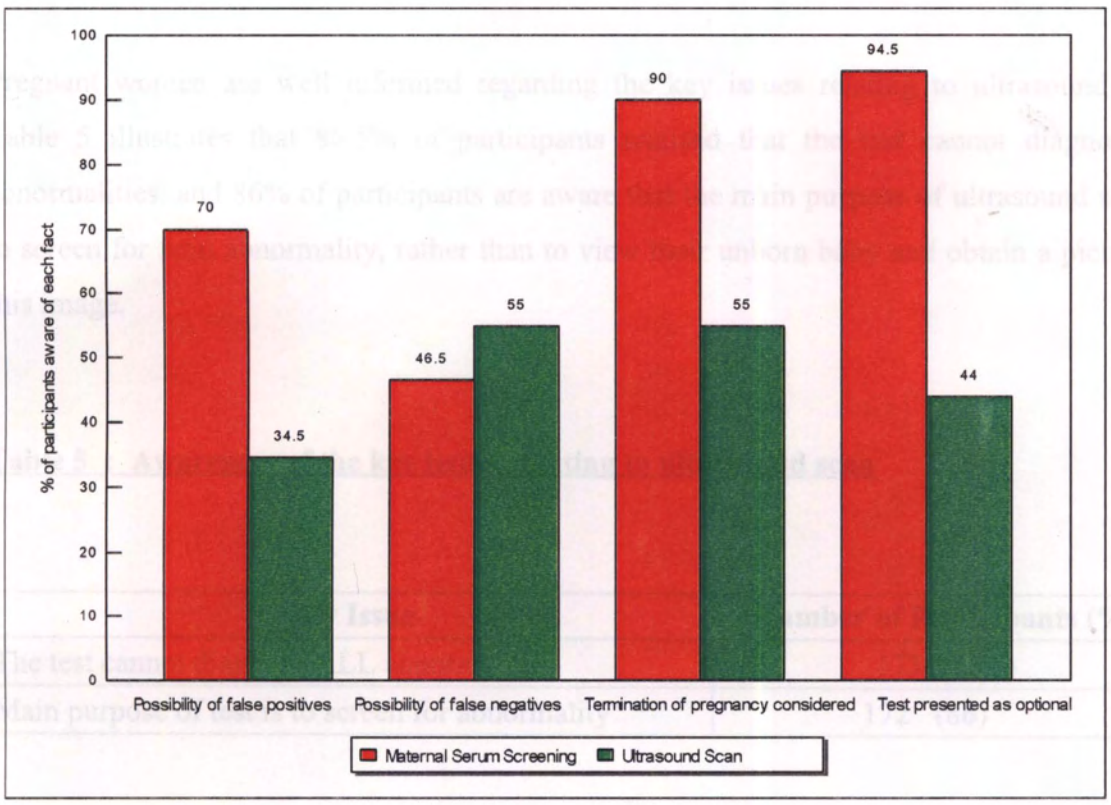
Age in Years	Professional (%)	Skilled (%)	Semi-Skilled (%)	Unskilled (%)	Unemployed (%)	Housewives (%)	Total (%)
< 20	-	-	3 (7)	3 (7)	8 (57)	-	14 (7)
21 - 30	8 (35)	22 (50)	29 (63)	27 (63)	5 (36)	11 (37)	102 (51)
31 and over	15 (65)	22 (50)	14 (30)	13 (30)	1 (7)	19 (63)	84 (42)
Total(%)	23 (11.5)	44 (22)	46 (23)	43 (21.5)	14 (7)	30 (15)	200 (100)

Table 3 : Distribution of Place of Booking

Place of Booking	Number of Participants (%)
Community	161 (80.5)
Hospital	39 (19.5)
Total (%)	200 (100)

The Royal College of Obstetricians and Gynaecologists (1993) define certain key issues relating to screening that pregnant women should be aware of, in order to make informed choices regarding their care. The study indicated that pregnant women are more aware of the key issues relating to maternal serum screening than ultrasound scan as shown in figure 1. There is, however, one exception: 55% of women are aware that ultrasound scan can produce a false negative result, but only 46.5% of women are aware of this fact in relation to maternal serum screening.

Figure 1 : A comparison of the awareness of key issues in relation to maternal serum screening and ultrasound scan.



Pregnant women are aware of the key issues relating to maternal serum screening as illustrated in table 4. There is however, one exception, where only 43% of participants realised that the results of amniocentesis can take up to four weeks to process.

Table 4 : Awareness of the key issues relating to maternal serum screening.

Key Issue	Number of Participants (%)
Test is not diagnostic	173 (86.5)
Amniocentesis offered to diagnose	186 (93)
Amniocentesis incurs 1% miscarriage risk	177 (88.5)
Results of amniocentesis take up to four weeks	86 (43)

Pregnant women are well informed regarding the key issues relating to ultrasound scan. Table 5 illustrates that 86.5% of participants realised that the test cannot diagnose all abnormalities, and 86% of participants are aware that the main purpose of ultrasound scan is to screen for fetal abnormality, rather than to view their unborn baby and obtain a picture of this image.

Table 5 : Awareness of the key issues relating to ultrasound scan

Key Issue	Number of Participants (%)
The test cannot diagnose ALL abnormalities	173 (86.5)
Main purpose of test is to screen for abnormality	172 (86)

The data obtained as illustrated was subsequently combined for each participant to produce a collective score. These scores are described as the total knowledge of key issues relating to maternal serum screening, and relate to eight questions; and the total knowledge of key issues relating to ultrasound scan which relates to six questions. Each score was then subject to statistical analysis in order to identify if age, parity, social class and place of booking were demographic indicators of knowledge.

The results of this study suggest that age is a strong demographic indicator of knowledge. Table 6 illustrates the mean and standard deviation values in relation to the awareness of key issues regarding maternal serum screening and ultrasound scan by age. A one way analysis of variance performed on these figures produced the values shown beneath the table, which indicated that it is statistically significant that the older the participant, the more knowledgeable she is in relation to both maternal serum screening and ultrasound scan.

Table 6 : The mean and standard deviation values in relation to the awareness of key issues regarding maternal serum screening and ultrasound scan by age group.

Age Group	Number of Participants	Mean (M.S.S.)	Standard Deviation (M.S.S.)	Mean (U.S.S.)	Standard Deviation (U.S.S.)
< 20	14	4.929	2.269	2.571	1.284
21 - 30	102	5.922	1.578	3.441	1.294
31 and over	84	6.560	1.347	3.905	1.518

Maternal Serum Screening (M.S.S.) - $F = 8.43$; $P < 0.005$

Ultrasound Scan (U.S.S.) - $F = 6.47$; $P < 0.002$

The results of this study suggest that social class is a strong demographic indicator of knowledge. Table 7 illustrates the mean and standard deviation values in relation to the awareness of key issues regarding maternal serum screening and ultrasound scan by social class. A one way analysis of variance performed on these figures produced the values shown beneath the table which indicated that it is statistically significant that the higher the social class, the more knowledgeable the participant is regarding maternal serum screening and ultrasound scan. The position of the 'housewives' group varied in the index of knowledge; between the skilled and semi-skilled groups in relation to serum screening, and between the professional and skilled groups in relation to ultrasound scan.

Table 7 : The mean and standard deviation values in relation to the awareness of key issues regarding maternal serum screening and ultrasound scan by social class.

Social Class	Number of Participants	Means (M.S.S.)	Standard Deviation (M.S.S.)	Mean (U.S.S.)	Standard Deviation (U.S.S.)
Professional	23	6.957	0.976	4.565	1.376
Skilled	44	6.455	1.320	3.727	1.370
Semi-Skilled	46	6.261	1.497	3.500	1.487
Unskilled	43	5.605	1.748	3.116	1.117
Unemployed	14	4.714	2.268	2.786	1.424
'Housewives'	30	6.167	1.392	3.733	1.484

Maternal Serum Screening (M.S.S.) - $F = 5.29$; $P = 0.000$

Ultrasound Scan (U.S.S.) - $F = 4.51$; $P < 0.001$

The results of this study suggest that the place of booking is not a demographic indicator of knowledge. Table 8 illustrates the mean and standard deviation values in relation to the awareness of key issues regarding maternal serum screening and ultrasound scan by place of booking. A pooled T-test performed on these figures produced the values shown beneath the table which indicated that there is no statistically significant difference between the knowledge possessed regarding both serum screening and ultrasound scan, by those who booked in the community and those who booked in the hospital. Therefore pregnant women who are counselled by hospital midwives did not possess significantly different levels of knowledge when compared to those who are counselled by community midwives.

Table 8 : The mean and standard deviation values in relation to the awareness of key issues regarding maternal serum screening and ultrasound scan by place of booking.

Place of Booking	Number of Participants	Means (M.S.S.)	Standard Deviation (M.S.S.)	Mean (U.S.S.)	Standard Deviation (U.S.S.)
Community	161	6.13	1.53	3.63	1.42
Hospital	39	6.08	1.90	3.36	1.46

Maternal Serum Screening (M.S.S.) - $T = 0.19$; $P < 0.85$; $DF = 198$

Ultrasound Scan (U.S.S.) - $T = 1.05$; $P < 0.29$; $DF = 198$

The results of this study suggest that parity is not a demographic indicator of knowledge. Table 9 illustrates the mean and standard deviation values in relation to the awareness of key issues regarding maternal serum screening and ultrasound scan by parity. A pooled T-test performed on these figures produced the values shown beneath the table which indicated that there is no statistically significant difference between the knowledge possessed regarding serum screening and ultrasound scan, by those participants who were having their first baby, and those who were having their second or subsequent baby.

Table 9 : The mean and standard deviation values in relation to the awareness of key issues regarding maternal serum screening and ultrasound scan by parity

Parity	Number of Participants	Mean (M.S.S.)	Standard Deviation (M.S.S.)	Mean (U.S.S.)	Standard Deviation (U.S.S.)
Primigravida	102	6.15	1.53	3.68	1.43
Multigravida	98	6.09	1.68	3.47	1.43

Maternal Serum Screening (M.S.S.) - $T = 0.24$; $P < 0.81$; $DF = 198$

Ultrasound Scan (U.S.S.) - $T = 1.02$; $P < 0.31$; $DF = 198$

Therefore, the results of the study indicate that age and social class are strong demographic indicators of knowledge in relation to both serum screening and ultrasound scan, whereas place of booking and parity are not.

The results of this study suggest that pregnant women have a significantly better knowledge base in relation to maternal serum screening, when compared to that of ultrasound scan. The mean and standard deviation values obtained from the scores of total knowledge of key issues relating to maternal serum screening and ultrasound scan for every participant collectively were 16.92 and 23.99 respectively. A pooled T-test performed on these figures produced a T value of 9.97 and a P value of less than 0.005, thus indicating that participants are significantly more knowledgeable regarding maternal serum screening.

Do pregnant women feel confident when making decisions?

Participants were also asked if they felt generally confident making decisions regarding the uptake of screening tests offered to them. 69% said they did generally feel confident, whereas 31% did not.

Comparing the knowledge possessed by participants regarding the practical aspects and the implications of each test.

In order to assess if participants are generally more knowledgeable regarding the practical aspects of screening, when compared with the implications of screening, two tables are drawn up to illustrate the distribution of responses in relation to maternal serum screening and ultrasound scan. A chi-square test was then performed on the data illustrated in both tables 10 and 11 in order to establish the statistical significance of the results. Table 10 illustrates that 86% and 69% of participants achieved a score of either three or four in relation to the practical aspects and the implications of maternal serum screening respectively. This illustrates that participants are generally more knowledgeable about the practical aspects of serum screening. However, overall knowledge of maternal serum screening is good, with 94% and 90.5% of participants scoring two or more in relation to the practical aspects and the implications of testing respectively. Indeed 37% and 38% of participants scored a top mark of four in relation to the practical aspects and the implications of serum screening respectively.

Table 10 : A comparison of the scores obtained in relation to the practical aspects and the implications of maternal serum screening.

Score out of Four	Number of Participants achieving this score re practical aspects (%)	Number of participants achieving this score re implications of testing (%)
0	1 (0.5)	4 (2)
1	11 (5.5)	15 (7.5)
2	16 (8)	43 (21.5)
3	98 (49)	62 (31)
4	74 (37)	76 (38)
Total	200 (100)	200 (100)

A chi-square test performed on these data illustrates that participants are significantly more knowledgeable regarding the practical aspects of maternal serum screening, when compared with the implications of maternal serum screening - ($x^2 = 22.898$, DF = 4, $P < 0.001$).

Table 11 illustrates that 83.5% and 45.5% of participants achieved a score of either two or three in relation to the practical aspects and the implications of ultrasound scan respectively. Indeed, in relation to the implications of ultrasound scan, 20% of participants failed to score at all. This illustrates that participants are generally knowledgeable regarding the practical aspects of ultrasound scan, but are markedly less aware of the potential implications of the procedure.

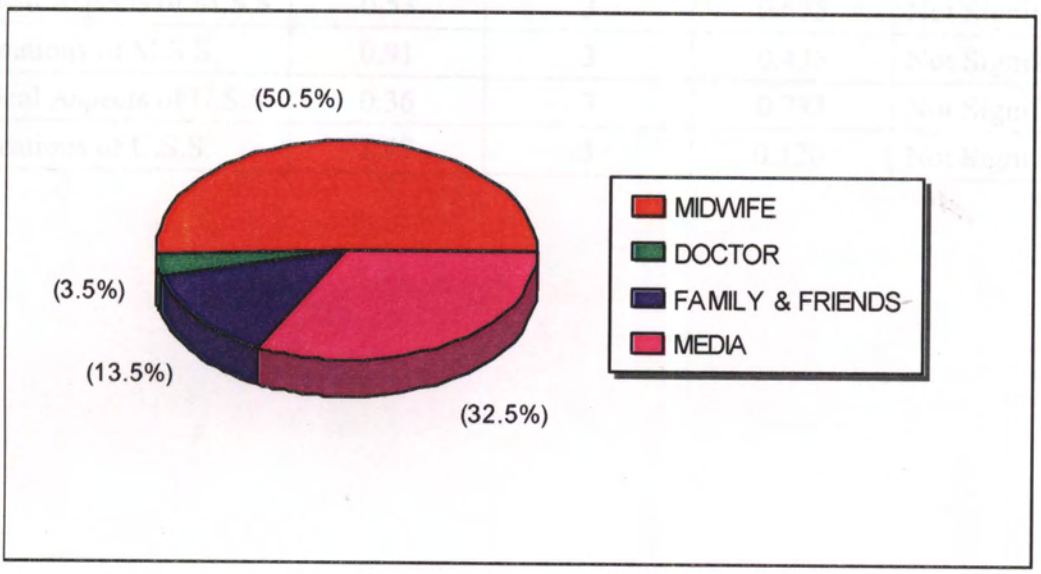
Table 11 : A comparison of the scores obtained in relation to the practical aspects and the implications of ultrasound scan.

Score out of Three	Number of participants achieving this score re practical aspects (%)	Number of participants achieving this score re implications of testing (%)
0	2 (1)	40 (20)
1	31 (15.5)	69 (34.5)
2	99 (49.5)	60 (30)
3	68 (34)	31 (15.5)
Total	200 (100)	200 (100)

A chi-square test performed on these data above illustrates that participants are significantly more knowledgeable regarding the practical aspects of ultrasound scan, when compared with the implications of ultrasound scan. ($x^2 = 72.215$, DF = 3, $P < 0.001$).

Figure 2 illustrates the data collected regarding where the participants considered they had obtained the most useful and helpful information in relation to maternal serum screening and ultrasound scan. Each participant selected her response from one of the four categories illustrated.

Figure 2 : Source of the most useful and helpful information



The above data were then subject to a one-way analysis of variance, in order to identify if the source cited as having given the most useful and helpful information had reflected in the knowledge base of each participant. Each individual's total score of maternal serum screening and ultrasound scan was considered, as well as the scores obtained in relation to the practical aspects and the implications of both tests. Table 12 illustrates that the source cited as having provided the most useful and helpful information had no statistically significant influence upon the knowledge of participants in relation to maternal serum screening and ultrasound scan. This was true for both the total scores obtained for each test, and for the scores obtained regarding the practical aspects and the implications of each test.

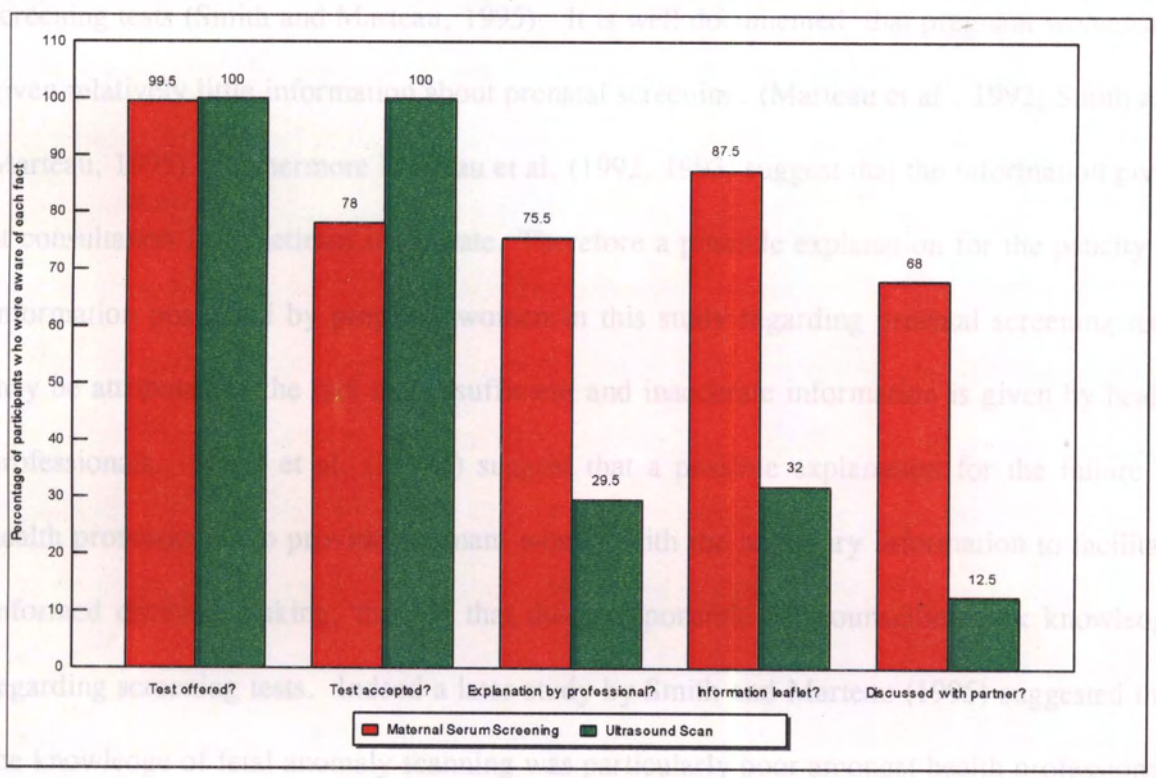
Table 12 : Analysis of variance using the scores obtained in relation to maternal serum screening and ultrasound scan, against the source of the most useful and helpful information.

Aspect of Knowledge	F Value	Degree of Freedom	P Value	Significance
Total Score - M.S.S.	0.46	3	0.709	Not Significant
Total Score - U.S.S.	1.55	3	0.202	Not Significant
Practical Aspects of M.S.S.	0.53	3	0.665	Not Significant
Implications of M.S.S.	0.91	3	0.435	Not Significant
Practical Aspects of U.S.S.	0.36	3	0.783	Not Significant
Implications of U.S.S.	1.97	3	0.120	Not Significant

Practical spects of how screening tests are offered.

Further data were also collected regarding the practical aspects of how both maternal serum screening and ultrasound scan were offered, and whether the offer of screening was accepted or not. Figure 3 illustrates that 100% of participants accepted the offer of ultrasound scan, whereas the uptake of maternal serum screening was lower at 78%. Furthermore the number of participants who received explanation from a health professional and the number who were given written literature regarding both tests, reflects the greater efforts that are currently made to present maternal serum screening to clients. Furthermore, only 12.5% of participants discussed having an ultrasound scan with their partner, whereas 68% discussed maternal serum screening with their partners.

Figure 3 : Practical aspects of how maternal serum screening and ultrasound scan were offered which may bear an influence on decision making.



CHAPTER FIVE

DISCUSSION

The results of this study indicate that pregnant women possess a limited knowledge base in relation to maternal serum screening and ultra sound scan. A significant finding of this study was that pregnant women are more knowledgable regarding maternal serum screening than they are in relation to ultrasound scan ($p < .0005$). These results parallel an earlier observational study of midwives' and obstetricians' routine consultations, which concluded that women are given markedly less information about fetal anomaly scans, than about serum screening tests (Smith and Marteau, 1995). It is well documented that pregnant women are given relatively little information about prenatal screening, (Marteau et al., 1992; Smith and Marteau, 1995). Furthermore Marteau et al. (1992, 1993) suggest that the information given at consultation is sometimes inaccurate. Therefore a possible explanation for the paucity of information possessed by pregnant women in this study regarding prenatal screening tests may be attributed to the fact that insufficient and inaccurate information is given by health professionals. Smith et al. (1994b) suggest that a possible explanation for the failure of health professionals to provide pregnant women with the necessary information to facilitate informed decision making, may be that those responsible for counselling lack knowledge regarding screening tests. Indeed a later study by Smith and Marteau (1995) suggested that the knowledge of fetal anomaly scanning was particularly poor amongst health professionals in comparison with their knowledge of maternal serum screening, and that they lacked the communication skills necessary to provide such information. Although the current study did not assess what information midwives and obstetricians gave to pregnant women, in the light

of previous literature, it is possible to propose that the limited knowledge of the clients may well reflect the fact that those responsible for counselling lack knowledge themselves in relation to screening tests.

The fact that women are more knowledgeable about serum screening than ultrasound scan, may well rest with the perception of these tests by both the health professionals responsible for their implementation, and the women to whom they are offered. Maternal serum screening is a relatively new test in most maternity units, and its initial implementation may have motivated staff to seek out information regarding its use. Furthermore, on the introduction of this test, health trusts may have developed screening practice along deontological principles by ensuring that key staff are given training on how to present information to women regarding maternal serum screening. Such an approach enables health professionals to be guided by the empowerment approach to health education by giving pregnant women the information they need in order to make informed choices. However, Marteau (1990) found that health professionals rarely received any formal training in relation to presenting prenatal screening tests. Furthermore, health professionals may also fail to provide adequate information regarding ultrasound scan, because they view the test very positively. Indeed, it is a physically non invasive procedure, involving little or no discomfort, and Smith and Marteau (1995) point out that it is considered to be a positive psychological experience for pregnant women. Moreover, the scan does provide useful information for antenatal staff, such as the expected date of delivery and growth rate of the fetus, which contributes to monitoring the safe progress of the pregnancy. For these reasons, health professionals may not perceive ultrasound scan primarily as a test which screens for fetal abnormality, and may therefore be reluctant to give women information which might discourage uptake of the procedure (Smith and Marteau, 1995). Indeed Marteau (1991)

suggested that a positive attitude towards testing by health professionals resulted in high levels of test uptake, but not necessarily informed uptake. The attitude of health professional as illustrated in Marteau's study in 1991 reflects the more traditional biomedical model of health education, where clients were informed regarding the test, but were persuaded towards accepting the procedure.

Proud (1995) stresses that many pregnant women view the prospect of ultrasound scan very positively. She suggested that women may accept scan because it offers the first opportunity to see their unborn baby and this is perceived as a social event, a high spot within a long pregnancy, which is often shared with partners, family or friends. Green (1991, cited in Proud, 1995) cautions that such beliefs can lead women to accept ultrasound scan, and that such decisions will bear no relation to the original reason underpinning the offer of scan, that is, to screen for fetal abnormality. The responsibility of ensuring that misconceptions regarding screening do not occur rest with the health professional (Smith and Marteau, 1995), but the literature suggests that this opportunity is frequently neglected or poorly implemented.

The apparent lack of knowledge regarding ultrasound scan and its implications as a screening test may further rest with the way that the test is offered by health professionals. Figure 3 illustrates that although all participants in the study were offered and subsequently had a scan, less than a third ever received any explanation regarding the procedure and only thirty-two percent of participants were given any written information. These figures closely correlate with a study by Proud et al. (1995). Therefore, it is possible that pregnant women are being denied the opportunity to make informed decisions regarding ultrasound scan, because health professionals are failing to relay the necessary information to facilitate such

decisions. Furthermore, the fact that eighty-seven and a half percent of participants in the current study did not enter into any form of discussion with their partners regarding the uptake of scan, and that sixty-six percent of participants did not realise that the offer of a scan was not compulsory, may further indicate that women remain largely ignorant of the potential implications that can accompany ultrasound scan. We could speculate that this lack of knowledge renders clients unaware of the important issues regarding the test, which warrant discussion and consideration. Moreover, in a study by Proud et al. (1995), health professionals stated that they did not routinely offer pregnant women any information regarding the implications of ultrasound scan as a screening procedure, because the women had expressed a desire to have a scan. However, such withholding of information is a practice criticised by Beech (1992), because it leads to ownership of information and denies women the opportunity to make informed choices regarding their care. Moreover, it may well leave the health professional open to litigation, a view endorsed by Dimond (1994). Indeed such practice represents the paternalistic approach of the biomedical model of health which is guided by utilitarian principles, where health professions persuade clients to accept procedures which they deem necessary to ensure the absence of disease, and in the case of prenatal screening, the absence of fetal abnormality. Moreover, such practice serves to misguide the client, which restricts personal autonomy and undermines competence in informed decision making, thus representing cultural iatrogenesis as described by Illich (1977). Indeed, this practice must be challenged if the attainment of a healthy status for clients is to be achieved (Illich, 1977). In the context of prenatal screening, this involves guiding professional practice in line with deontological principles, where the empowerment approach to health education is utilised. Thus clients are able to understand and consider the complex moral and ethical issues, in order to arrive at an informed decision which truly reflects their desired intention. Furthermore, it is important to stress that the failure of

health professionals to enable pregnant women to give informed consent in relation to prenatal screening, has legal implications. As Purtilo (1993) points out, the legal concepts of battery, disclosure, the fiduciary relationship, the common law right to self-determination and the constitutional right to privacy can all be breached. However, it is reasonable to suggest that the fear of criminal prosecution should not ultimately motivate the health professional to guide his or her practice in line with an empowering approach to health education, but his or her commitment to the ethical principle of non-maleficence as specified in the Professional Code of Practice (UKCC, 1994).

It is also possible to speculate that health professionals are failing to counsel women regarding ultrasound scan because the test has been well established for some years, and when it was originally introduced, the more paternalistic approach of utilitarianism had prevailed, which did not prioritise the client's right for information to facilitate informed consent. Indeed this study suggests that practice has not yet evolved to embrace a deontological approach, where staff are trained to give women the information regarding ultrasound scan which would enable them to exercise their autonomy by making informed decisions regarding test uptake.

The higher levels of knowledge possessed by the participants regarding the key issues which underpin maternal serum screening, may also be explained by the way the test is offered by health professionals. The current study indicates (Figure 3) that three quarters of participants were given a verbal explanation of serum screening by a health professional, and that eighty-seven and a half percent of participants were given written literature regarding the test. Although these figures reflect the greater efforts of health professionals to give clients information regarding maternal serum screening, when compared with the same data

regarding ultrasound scan, it does illustrate that one quarter of participants were not given any verbal explanation and twelve and a half percent of participants were not given any written information regarding serum screening. For these individuals, the health professionals concerned had failed to relay the information required to facilitate informed decision making regarding serum screening.

The fact that ninety-four and a half percent of participants realised that serum screening was optional, and that sixty-eight percent of participants discussed the prospect of having this test with their partner, may reflect a greater understanding that there were issues relating to the procedure which required consideration. Just over three quarters of participants accepted the offer of serum screening. This lower uptake, when compared to that of ultrasound scan may reflect the fact that potential participants were more knowledgeable about serum screening, and were therefore more cautious when considering the test. Conversely, the hundred percent uptake of ultrasound scan may suggest that participants were not aware of the potential negative implications of the procedure and therefore unquestioningly accepted the procedure. This view is supported by Round et al. (1993), but contested by Marteau et al. (1989), who concluded that the better informed women are, the higher the uptake of prenatal screening.

The high uptake of ultrasound scan, when compared to maternal serum screening may be further explained by the fact that ultrasound scan is offered on an opt-out basis. Specifically, every women is routinely sent an appointment for scan, on booking for pregnancy care. Conversely, maternal serum screening is theoretically offered on an opt-in basis. During initial consultation with the midwife, the test should be offered and explained to the client, so that arrangements can then be made for the blood to be taken, should the offer of testing

be accepted. This fundamental difference in the way these two tests are offered, could potentially send non verbal messages to participants which may influence test uptake. For example, the client may not stop to think that ultrasound scan may be declined, assuming that the procedure is compulsory. Moreover, the fact that a client has to take action to decline the procedure, may inhibit her from doing so. Conversely, the opportunity to decline serum screening is actively presented as an option, thus implying that it is acceptable to consider such an option.

A further significant finding from the study was that women were more knowledgeable regarding the practical aspects of both tests, but were significantly less knowledgeable regarding the implications of each test, which could inform their decision on test uptake. Indeed, these results accord closely with those found by Smith et al. (1994a). Table 11 illustrates that eighty-three and a half percent and forty-five and a half percent of participants achieved a score of two or three in relation to the practical aspects and the implications of ultrasound scan respectively. Moreover, twenty percent of participants failed to score in relation to knowledge of the implications of ultrasound scan. Table 10 reflects a similar distribution of knowledge, with eighty-six percent and sixty-nine percent of participants achieving a score of three or four in relation to the practical aspects and the implications of maternal serum screening respectively.

A study by Marteau et al. (1992) suggested that the higher levels of knowledge regarding the practical aspects of serum screening and possible diagnostic tests which are offered following a positive result, may reflect the areas which health professionals concentrate upon during counselling. Indeed in Marteau's study the pattern of women's knowledge reflected the observed emphasis of informing women about the practical aspects of screening during

consultation with health professionals. Moreover, information about the likelihood and implications of possible results was not routinely presented. The current study could not offer explanations which may account for the distribution of knowledge in relation to prenatal screening, because unlike Marteau et al. (1992), consultations were not taped, therefore the information specifically imparted by health professionals was not apparent. However, it is possible to suggest that health professionals are giving pregnant women information which relates to the practical aspects of screening, and failing to relay information regarding the more complex issues which can arise from being screened. The results of a study by Smith and Marteau (1995) serve to support this suggestion by concluding that health professionals were more reluctant to disclose information to clients that was complex. Indeed it is reasonable to suggest that knowledge regarding the implications of screening is thought to be more complex than the knowledge relating to the practical aspects of screening. Therefore health professionals are required to convey such information to clients in a clear and precise manner, in order to facilitate complete understanding and ultimately informed consent.

The current study suggests that information on the potential for receiving false negative results appears to have been neglected, thus failing to prepare women for the possible event of giving birth to an affected child following a low risk result (Figure 1). Furthermore, only forty three percent of women were aware that the results of amniocentesis can take up to four weeks to process. In failing to understand this, women are not aware that they could be faced with the dilemma of considering termination of pregnancy at twenty weeks gestation or later. Furthermore, the movements of the fetus may be felt by the mother at this gestation and this may further contribute to the anguish felt, when faced with making a decision regarding termination at this stage of pregnancy.

Figure 1 illustrates that only fifty-five percent of participants had ever thought that they may have to consider termination of pregnancy as a direct result of ultrasound examination. This emphasises the fact that many women are failing to view this procedure as a screening test, even though paradoxically, eighty-six percent realised that the main purpose of scanning was to look for fetal abnormality, rather than to view their baby and have a photograph. When considered collectively with the poor understanding of the potential of false positive and false negative results, this fact indicates that women do not understand the complex underlying issues which can emerge and require consideration, as a result of scanning. The similar trend reflected in the knowledge of serum screening, may suggest that health professionals are either not giving this information at consultation (Marteau et al., 1992), or that they lack the communication skills to present effectively such information to women. Moreover, the study indicated that sixty-nine percent of participants felt confident when making decisions regarding prenatal screening. Therefore, women are largely unaware that they are not making fully informed choices regarding prenatal screening. Indeed, this misconception would not be challenged, unless the woman is recalled for further investigation as a result of the initial procedure. The key point that emerges from this is that women cannot be prepared for the rare, but nevertheless significant events that may result from electing to accept screening in the first place. It is reasonable to assume that the lack of knowledge possessed by pregnant women in relation to prenatal screening and their resulting inability to make informed choices are not the result of malicious intent on the health professionals' behalf, who probably believe that they are offering these tests in accordance with the deontological concepts of beneficence (promoting good) and non-maleficence (doing no harm). Nonetheless, the absence of informed consent must be addressed because it remains unethical to deny women their right to be treated as individuals who determine their own lives. Such a situation violates personal autonomy, which is central to informed consent and

indeed to deontological principles.

Tables 6, 7, 8 and 9 indicate that the study found the demographic variables of social class and age to be strong predictors of variance in knowledge regarding the awareness of key issues in relation to both tests, whereas parity and whether the participant was counselled by a hospital or community midwife were not. These findings only partially concur with an earlier study by Smith et al. (1994a) which suggested that the demographic variables of age, social class and parity were weak indicators of variance in knowledge. The differing outcomes of both studies may be explained by differences in the study designs. Smith et al. (1994a) used a multiple choice questionnaire, whereas the current study utilised structured interviews. Furthermore, Smith et al. (1994a) designated social class distribution by each individual's partner's occupation, whilst this study used each participant's occupation to denote social class, because there were a minority of individuals who did not have partners. However, it was felt that this method of identifying social class was a more accurate indicator of each woman's own class, and this was considered appropriate because the study was concerned with the knowledge of the women themselves and not their partners. Moreover, the current study was conducted at one centre, whereas Smith et al. (1994a), conducted their study at five different centres and was significantly larger in terms of sample size. However, the levels of statistical significance in the current study, where knowledge variance was associated with social class and age, were of a high confidence level ($p < 0.002$).

It may be possible to explain the paucity of information possessed by the less privileged social classes as a two dimensional problem. Firstly, the current system of counselling patients prior to screening is failing to target this particular group and is not addressing their

individual and specific requirements. Secondly, the client may not be assuming her responsibility to ensure that she is well informed regarding prenatal screening and is therefore confident to make informed decisions. Indeed, in order to avoid blaming individuals, it is possible to speculate that clients are not aware that such a responsibility exists or is necessary. However, Whitehead (1992) does point out that the more privileged social groups are more likely to actively take up preventative and screening services. Moreover, Tudor Hart (1971) observed that medical resources are generally least available where they are needed most. Whitehead (1992) also warns against individualistic "victim blaming", stating that the social context of each person's life is an important factor in the ability to adopt healthy attitudes. Indeed, in the context of prenatal screening, if an individual has problems with housing and finance, exacerbated by the fact that she is an unsupported single parent, she may need more help and support from health professionals to alleviate her initial social problems, before she is able to dedicate time and effort into accurately considering screening procedures. Indeed, Pearson et al. (1992) reiterated this point by stressing that the uptake of health care services is influenced by the co-ordination and scheduling of other important daily tasks and related activities, which requires skills in creativity and negotiation. Thus, the autonomy of an individual is not absolute, but is attainable to a greater or lesser extent depending upon the social environment of those concerned. Naidoo and Wills (1994) also make explicit the sense of responsibility to others in the ability of an individual to exercise personal autonomy. The deficit in knowledge amongst the less privileged social classes, may indicate that recent government initiatives such as The Patients' Charter (DOH, 1991), are failing to ensure equitable distribution of resources, in particular the targeting of specific groups who need more help and support.

It was interesting to note that the levels of knowledge possessed by the group termed 'housewives', lay between the skilled and the semi-skilled group for serum screening; and between the professional and skilled group for ultrasound scan. The study did not collect data regarding the previous occupations of this group, and therefore we are limited to suggesting that this distribution of knowledge may be attributed to the fact that group members came from the respective social classes which denoted a fairly high position within the knowledge index. The higher levels of knowledge within this group might be explained by the fact that many participants came from higher socioeconomic groups, because their partners were in a position to financially support the family on a single income. This suggestion may be further supported by the higher representation of housewives within the older age group - sixty-three percent were aged thirty-one years and over (Table 2). This might imply that their partners (who are likely to be of a similar age), have progressed sufficiently within their occupations to enable the family to actively choose to live on a single income. Although generalisations cannot be made with the data available, it may be possible to speculate that the elevated knowledge of the group termed 'housewives' might correlate with the fact that a significant number of participants were more affluent and came from an older age group. Indeed the study suggests that the more privileged social classes and increasing age were strong demographic indicators of higher levels of knowledge.

The study also illustrated that the older the participant, the more knowledgeable she was likely to be regarding prenatal screening. This may be explained by the fact that the wider educational and career opportunities available to women today, in conjunction with delayed marriage and more reliable contraception, has resulted in more women becoming pregnant for the first time at an older age (Bureau of Census, 1989 cited in Alexander et al., 1993). Indeed data from the current study indicates that thirty-two percent of participants were

pregnant for the first time aged thirty-one years and over. Tuck et al. (1988 cited in Alexander et al., 1993) points out that there is an over representation of women from higher socioeconomic groups amongst primigravidae, aged over thirty-five years who have elected to be childless until this time. The distribution of age and social class within the current study is defined in table 2, which illustrates that sixty-five percent and fifty percent of participants in the professional and skilled groups respectively, were aged thirty-one years and over. It is therefore possible to suggest that the higher levels of knowledge amongst the older population might link up with the fact that they also belong to a higher socioeconomic group. Indeed, it is interesting to note that it is not possible to make further links with this trend and parity. One might expect multigravida who have previously experienced prenatal screening, to be more knowledgeable. However, the fact that 32% of primigravidae were aged 31 and over, might have served to elevate the knowledge base of this group. Similarly 47% of multigravidae were of the younger age group 21-30 years, and this representation may have decreased the knowledge base of the multigravidae group. The age factor amongst primigravidae and multigravidae may have combined to produce no significant differences in knowledge levels for these groups.

The fact that parity was not a strong indicator of knowledge accords with the results of a study by Smith et al. (1994a). This might be explained by the fact that health professionals responsible for counselling, are presuming that women in their second or subsequent pregnancies have previously experienced screening procedures, and therefore will not require as detailed explanation as a first time mother. The problem with such an assumption is that women who made uninformed decisions previously, are allowed to repeat the process. Moreover, the pregnant women themselves may feel that they do not require further detailed explanation, because of their previous experience. However, this assumes that informed

decisions were made during the first pregnancy, and this attitude does not accommodate the rapidly advancing technology that is continually changing the issues underpinning each screening procedure. Moreover, both health professionals and the women themselves, might well be aware of the fact that a primigravida is largely ignorant of the issues surrounding prenatal screening. Consequently a more constructive effort may be made by health professionals to impart the required information to this group, and clients themselves may actively seek out this information.

There was no significant difference between the levels of knowledge possessed by participants who were booked in hospital and therefore counselled regarding prenatal screening by a hospital midwife, and those who were booked in the community, and counselled by a community midwife. This indicates that counselling services within each environment are of comparable effectiveness. Both hospital and community midwives receive the same basic professional training, therefore the standards to which they present screening procedures are likely to be similar. Indeed, since both groups are employed by the same health trust any opportunities for post basic training offered regarding prenatal screening will have been the same. Moreover, those who are booked by hospital and community midwives are allocated in accordance with the county in which they live, therefore no bias may be instilled by the distribution of age, or parity or social class.

Khalid et al. (1994) point out that current practice regarding the implementation of prenatal screening ensure that the main responsibility for counselling clients falls upon the midwife. The current study indicates that half of the participants cited the midwife as the source of the most useful and helpful information (figure 2), and this may reflect the fact that the midwife bears within her role the major responsibility for counselling. A positive feature of this

study was considered to be that it acknowledged that pregnant women do not obtain their information regarding prenatal screening from health professionals alone. Indeed a third of participants cited the media as the source of the most useful information. The influence of the media is also acknowledged by Jacoby (1988, cited in Proud and Murphy-Black, 1995).

Table 12 illustrates that the source cited as having provided the most useful and helpful information had no statistically significant influence upon the knowledge of participants in relation to all aspects of both maternal serum screening and ultrasound scan. This was true for both the total scores obtained for each test, and for the separate scores obtained regarding the practical aspects and the implications of each test. It would be unethical for health professionals to dictate to clients where they obtain their information regarding screening, and what information they require to facilitate informed consent. Such an approach reflects authoritarian ideology associated with traditional health education, where health professionals actively persuade clients to take up services that are deemed desirable in line with the biomedical model of health, that is, the absence of disease. This is criticised by Naidoo and Wills (1994) because it actively removes health decisions from the people concerned, and Illich (1976) condemns this approach for predisposing dependency on medical knowledge. This action is unethical because it fails to acknowledge the patient's right to autonomy and ultimately, informed consent. However guidelines do exist regarding what information should be given to pregnant women regarding screening (RCOG, 1993). These serve to set universal optimum standards and further help to organise services in the light of the latest available knowledge. Nonetheless, the results of this study suggest that current methods of implementing prenatal screening are largely following a medicalized approach which is failing to enable clients to give informed consent. The results of the current study indicate that clients are equally well informed, regardless of whether they obtained their

information from a health professional, the media, or family and friends.

The medicalized approach is directly challenged by the aims of Changing Childbirth and The Patient's Charter (Department of Health, 1993; 1991), which advocates the central role of the pregnant woman in making choices regarding her health care. Such an approach advocates that the midwife or obstetrician, within his/her role as a health educator, provides the client with the relevant information which subsequently enables her to identify her needs and work towards an informed choice, even if the health professional does not consider the chosen option to be the appropriate one. This approach is viewed by Tones (1992) as embracing the principle of self-empowerment, where modified authoritarianism exists in the giving of information, and is united with voluntarism when clients are actively supported, but not persuaded, by health professionals in attaining their desired choice. Moreover, Naidoo (1986) blames individualism that has been associated with the traditional biomedical approach, as the cause of its failure to address the real issues associated with health. Therefore the future of facilitating autonomous decision making among pregnant women regarding prenatal screening may lie in not only providing the necessary information, but also in supporting her to actively choose the desired option. In this way, the client is in a position to give informed consent regarding screening procedures.

Moreover, the failure to facilitate informed consent has basic legal and ethical implications. As Purtilo, (1993) emphasises, the laws relating to battery, disclosure and the judiciary relationship can all be breached, as a result of uninformed decision making. Furthermore, respecting the patient's right to informed consent safeguards each individual's right to be respected as a person, thus retaining human dignity and integrity. In this way every person is capable of making choices, thus exercising her right to autonomy and the ability to act

upon moral grounds. However, Campbell (1990 cited in Naidoo and Wills, 1994) warns that the health professional must not persuade the client in any way and information must be accurate and unbiased. Indeed Proud and Murphy-Black (1995) suggest that some health professionals view the autonomy of the patient as a threat to their own autonomy. These attitudes are undesirable in the context of informed decision making, because they reflect the paternalistic attitudes associated with authoritarianism and the traditional methods of health education.

Offering prenatal screening to detect fetal abnormality will inevitably place some pregnant women in a situation where they must face making complex moral and ethical decisions regarding their pregnancy. In particular, where a definite diagnosis of fetal abnormality has been made, they will have to make decisions regarding possible termination of pregnancy. Alternatively, there are circumstances where a definite diagnosis is uncertain and fetal abnormality is implied, but the consequences of such findings would not be certain until after birth. Naidoo and Wills (1994) state that, in these situations, attempting to apply the key principles of doing good and avoiding harm is not a simple process. They highlight the fact that screening cannot ensure a good outcome and therefore represents the tension between beneficence and non-maleficence. In this way, screening is seen as good, but is not without harm and for this reason, Duncan (1990) argues that ensuring that clients make informed decisions having fully considered the potential advantages and disadvantages of testing, is of paramount importance. Whilst good professional practice in ensuring that women give informed consent cannot change the fact that screening can present pregnant women with complex and difficult choices, it does serve in the best interests of clients by enabling them to appreciate and understand both the positive and negative implications of being offered choice.

Proud (1995) emphasises that screening programmes are offered with the aim of detecting the abnormal or the diseased, so that action may be implemented to either eradicate the identified problem or to offer treatment, thus improving the outcome. This is viewed as beneficial to the majority of the population, and in the case of prenatal screening, this results in a reduction in the perinatal mortality and morbidity levels (Proud, 1995). Naidoo and Wills (1994) make the point that because we know that screening cannot guarantee a favourable outcome, it therefore falls more in line with utilitarian principles of producing the greatest happiness for the greatest number. However, they do question whether or not harming the lesser number in the overall attempt of producing the greatest good can be justified. Potential harm to clients as a result of screening may include the consequences of having to face a decision regarding termination of pregnancy, or the trauma of receiving a false positive or false negative result. Indeed, key philosophical questions arise from this issue about freedom and its limits, specifically, should the interests of the majority always take precedence over those of each individual?

It could certainly be argued that the current system of implementing prenatal screening is underpinned by utilitarian principles, as cited by Naidoo and Wills (1994). The literature suggests that informed decision making is resulting in high levels of anxiety and this is particularly true for those receiving false positive results from screening (Stratham and Green, 1993). Therefore utilitarians would justify inflicting harm upon the minority who receive false positive results, by citing the benefits of reassurance which are enjoyed by the majority of the screened population. However, if pregnant women were empowered to make fully informed decisions regarding screening, as a result of health professionals facilitating and supporting such autonomous action, then such an approach may fall in line with deontological theory. This is because the worth of each individual pregnant woman has been

considered and those responsible for counselling have ensured that the client is fully aware of the potential advantages and disadvantages of screening. Thus it is acknowledged that the outcome of screening cannot be guaranteed as favourable, but each individual fully understands this fact and makes her own decision accordingly. Moreover, from a deontological perspective, there is no obligation to accept the tests on offer, whereas utilitarian ideology advocates that women are morally obliged to join a programme which offers benefits to the majority, even if a minority of the population is harmed in the process.

The theories underpinning the empowerment approach to health education are particularly appropriate when planning future implementation of screening services, because they move away from the individualist approach of the biomedical model of traditional health education by giving individuals the opportunity to make autonomous decisions. The concept involves equity in empowering people to make choices and to determine their own lives, thus promoting the development of personal autonomy. Although the aims outlined by Changing Childbirth (Department of Health, 1993), closely follow this ideology, clearly the literature indicates that current services offering prenatal screening do not promote informed consent and autonomy. The empowerment approach to health education which is set within the broad political spectrum of health promotion, will require patients to move away from their traditionally passive role in health care decisions, towards a more active approach, whilst health professionals must accommodate this change in behaviour by adopting a supportive, rather than a directive and controlling role.

Kelly et al. (1993) suggest the integration of environmental, social, organisational and individual issues when planning health promotion. This concept parallels those of the World Health Organisation (1984), and further complements the model of health promotion

developed by Tannahill (1985), which involves the overlapping spheres of health protection, health education and prevention. Indeed, this model would serve to guide future developments in the implementation of prenatal screening, providing that the criticism by Adams (1994) is upheld. He states that the key emphasis on the medical model and behavioural change cannot be accommodated by certain groups and that social and economic factors exert the greatest influence upon the development of healthy attitudes. Furthermore, these social ideologies are closely linked with the radical approach described by Tones and Tilford (1994), who also reject the medicalized model and warn against blaming individuals who are not in a position to adopt healthy options. Therefore, the development of services guided by health promotion, health education and prevention (Tannahill 1985) could be combined with radical approach described by Tones and Tilford (1994) to actively facilitate traditionally deprived groups to make informed decisions regarding prenatal screening.

An understanding of how people process information will serve to guide future developments in the empowerment approach to health education, where patients are able to progress from a passive to an active role in decision making and ultimately to the attainment of informed consent. Whilst all models of behavioural change identify common variables, it is the Health Belief Model (Becker, 1974) which highlights the function of beliefs in decision making, that would serve to guide practice regarding prenatal screening. The model suggests that decisions are influenced by evaluating feasibility by weighing up the potential benefits against cost. This may include considering beliefs regarding individual susceptibility and severity of a happening, and the effectiveness of any action taken. Therefore, peoples' perception and assessment of risk is a central feature of this model. Naidoo and Wills (1994) state that perception of risk is influenced by personal experience, ability to control the situation and perception of the threat. However, they state that in many situations people have an

unrealistic optimism that "*it won't ever happen to me*". An awareness of how people make decisions is thus invaluable in designing the presentation of information which could inform womens' decisions regarding prenatal screening. Indeed as suggested in the Health Belief Model, this would cue people into taking the issues seriously, thus spending time and effort on the consideration that is required to weigh up the issues regarding screening, therefore facilitating informed consent.

CHAPTER SIX

CONCLUSION

To conclude, there is a need to revisit the issue of informed consent, a concept which lies at the heart of this study. Autonomy is the key principle which underpins informed consent and when this is applied to offering pregnant women screening tests, it involves empowering them to have a choice in their care. However, as the study suggests, pregnant women have a limited knowledge base in relation to both maternal serum screening and ultrasound scan, thus the choice they are offered is rendered invalid. The doctrine of informed consent can be further problematised because not only does it involve how much information should be given to pregnant women, but also how clients process and assimilate this information in order to achieve an understanding of the issues concerned. Indeed, although the study did not directly assess what information was given to clients by health professionals, it did suggest that women do not completely understand the practical elements and especially the implications of being tested. Furthermore, knowledge in relation to ultrasound scan was significantly poorer than the knowledge of maternal serum screening.

Roelofsen et al. (1992) point out that serum screening is often viewed by pregnant women as a means of reassurance and the obvious thing to do because it is offered. However, those who are offered screening are unaware of the potential disadvantages, and in their quest for reassurance, may find themselves unexpectedly faced with difficult choices and dilemmas. A situation where pregnant women are not able to give informed consent compels us to think about the fact that they are expressing a desire to be offered screening, as suggested by Fairgrieve in 1992, but this expression may not reflect their true intention. Indeed, superficially it may appear that the advances in technology which result in the availability of

ever increasing numbers of screening procedures, is actively sought by pregnant women. However, it is reasonable to speculate that if women were aware of both the advantages and disadvantages offered by the technology, then they might not be so keen to encourage its implementation. This view is supported by Farrant (1985, cited in Homans, 1985) who points out that motives behind supply and demand don't necessarily correspond. Thus, it is essential to ensure that informed consent remains central when offering prenatal screening, so that those who elect to use the medical technology, are fully aware of its implications. Moreover, the theory underpinning government policy as stipulated by the Department of Health in 1993, is to minimise the financial burden imposed upon society by congenital abnormality. It is therefore possible to suggest that politicians are exerting a major influence upon the development of medical technology in order to satisfy their financial and political agendas. However, future directives in the development of such technology must respond to the views of those who will ultimately experience both the positive and negative attributes offered by the screening procedures that evolve.

In an attempt to address the problem of uninformed decision making, I propose that enabling women to progress from a passive to an active role in health care decisions, should form a central feature of pre-test counselling. Future care should therefore be modelled in line with deontological theory, where the autonomy of clients is both created and respected by health professionals. Such a concept is facilitated by setting counselling procedures within the empowerment approach to health education, where clients are not only given the necessary information regarding screening, but are also supported without persuasion by health professionals. Tones (1992) states that the principle of self-empowerment is central to making informed choices and as such, advocates an active role for women in decision making. Indeed the empowerment approach to health education avoids blaming individuals

for not taking the opportunities given to attain informed consent, because it is set within a broader political spectrum defined as health promotion. In this way, by considering the restrictions imposed upon each individual by his/her social circumstances, it is not presumed that individuals are free to exercise their autonomy. These principles promote the direction of resources towards the less privileged social groups and younger mothers, who are known to possess a poorer knowledge of screening when compared with their counterparts. The concept of self-empowerment and health promotion combine to complement the model of health promotion defined by Downie in 1990. This also parallels with the integration of health education, social and political themes as set out by the World Health Organisation in 1983.

The Health Belief Model as defined by Becker in 1974, further guides practice in enabling clients to move from a passive to an active role in their health care decisions. By focusing on the costs as well as the benefits of changing behaviour, it enables clients to change the way they may initially perceive screening, by dedicating time and effort towards reaching a choice which truly reflects their desired intention.

There are several key recommendations which arise from the results of this study, all with the ultimate aim of promoting a deontological approach. In conjunction with following the guidelines for counselling set down by the Royal College of Obstetricians and Gynaecologists in 1993, effective staff training is recommended as the cornerstone for achieving optimum standards in counselling. Such training should include establishing an adequate knowledge base on behalf of health professionals, as well as communication skills on how to effectively relay the complex issues associated with screening. Furthermore staff require skills to enable them to support clients through the decision making process without coercion or persuasion.

Indeed, Siddiqui, (1994) advocates that an understanding of the major ethical concepts relating to midwifery is fundamental in guiding practice and promoting the professionalism of midwifery.

Counselling procedures should evolve to ensure that everyone who is offered prenatal screening is given a comprehensive verbal and written explanation of each test, by a trained member of staff. A contact telephone number should also be given so that clients may request further information or support at a later date. Furthermore, the current system of offering ultrasound scan on an opt-out basis does not emphasise choice and should be offered, like maternal serum screening, on an opt-in basis. Moreover, the expertise generated by a specialist role is proposed to co-ordinate, monitor and evaluate service provision.

As the remit of health service extends to include more prenatal screening, with greater emphasis upon client involvement in decision making, it is paramount to ensure that the autonomy to which women are lawfully and morally entitled is facilitated by informed decision making. Indeed purchasers could stipulate within contracts that those responsible for implementing prenatal screening services should be fully prepared for their role of providing clients with advice, support and information at all stages of screening and diagnosis.

In the future, further studies will be indicated to evaluate the introduction of amendments made in the design and implementation of screening services. In particular the effect of practical amendments relating to how each test is offered and the introduction of education programmes for staff should be monitored. As part of this ongoing evaluation a qualitative

study design is suggested to gain a holistic view of individual experience by assessing the emotional implications of screening, particularly patient anxiety and satisfaction with service provision. Future study could also inform the effect of false negative results upon the adjustment of families to the birth of a child with handicap. To date there have been no studies dedicated to this area. Furthermore, future work is necessary to enable modifications in service provision to direct resources into addressing the needs of younger mothers and the less privileged social classes.

The implementation of screening programmes compels us to ask another important question: are we doing the right thing in offering these tests to women? For some, the offer of such tests epitomises choice, while for others it is the slippery slope to eugenics, where parents are presented with a conundrum of moral and ethical dilemmas, which would seem impossible for any reasonable person to deal with. Furthermore, there remains the question of what it does to mothers to give them the 'choice' of terminating a much wanted pregnancy, or to face the prospect of life with a baby whose prognosis is often painted as bleak by the text books. It can certainly be argued that the choice given to women by such tests is outweighed by the disadvantages of the loss of a much wanted infant, or the effect on society of the acknowledgement that the handicapped are not wanted or valued by us. Indeed, would it not be better to discard and reject the rapid advance of technology and leave women to enjoy their experience of pregnancy and childbirth unhindered? In this way, society might learn to accept and not prejudice or stigmatize the handicapped and their families. The absence of efforts made to detect fetal abnormality would reinforce the message to people with handicap that they are respected and supported as fully social beings. Moreover, in losing the choice to control the quality of our children, we gain the choice of simply accepting them as they are (Rotham, 1985). Furthermore, pregnant women would

be spared the agony of feeling pressurized by society to terminate a less than perfect baby. Indeed the perception of mothers as vessels for the production of perfect children serves to accentuate problems for those who despite screening still bear an affected child (Stacey, 1988).

On the other hand, it could be argued that the disadvantages resulting from the use of developing technology, are outweighed by the fact that women are ultimately given the choice to decide for themselves. Indeed the offering of such choices is never easy and always involves difficult decisions. A key question arises of whether it can be justified to deny women access to existing technology. Indeed Fairgrieve (1992) suggests that women are actively demanding the continued use of prenatal screening despite the costs. In Fairgrieve's study nearly eighty percent of women who had received an 'at increased risk' result stated that they would have serum screening in a future pregnancy, and ninety-four percent confirmed that the test should be available to all, despite their experiences. Certainly the implications of providing women with technical-medical information involves many difficult decisions and dilemmas. Indeed we can not be sure that the benefits of offering pregnant women prenatal screening are outweighed by the costs, because as Naidoo and Wills (1994) stress, every individual has differing moral and ethical values, according to their culture, past experience and their social environment. As health professionals, we must challenge the paternalistic approach of assuming the right to decide what is best for clients. Moreover our role must be centred on enabling clients to exercise their autonomy in making informed choices, by following deontological theory which is central to the empowerment approach of health education. In this way, clients are able to make choices, and a culture can evolve where it is equally practical and pleasant for clients to refuse as well as accept care. Ultimately women are therefore in a position to decide for themselves whether to

accept the choices offered by medical technology or to decline these choices and simply accept their pregnancy without investigation.

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APPENDICES

Appendix One - Prenatal Screening Study - Information Sheet

Appendix Two - Consent Form

Appendix Three - Maternal Serum Screening - Interview Guidelines

Appendix Four - Ultra Sound Scan - Interview Guidelines

COUNTESS OF CHESTER HOSPITAL

PRE-NATAL SCREENING STUDY

INFORMATION SHEET

Welcome to the Countess of Chester Hospital

We are currently conducting a study, which assesses the information pregnant mothers use to decide whether or not to have an ultra sound scan of their baby, or to have the blood test for Downs Syndrome.

The aim of the study is to analyse how much pregnant mothers know about each of the above tests and then to draw some conclusions on whether the tests are adequately explained. The results from the study will be used to make improvements in the way doctors and midwives explain each test to pregnant mothers and to provide better information leaflets.

Should you agree to participate in the study, we will require approximately 10-30 minutes of your time. There will be an informal interview with Diane Lee (study midwife) who will discuss how much you know about the tests and what factors are involved in helping you to make a decision..

Thank you for considering this invitation to take part in our study. Please note that participation is entirely voluntary and your future care will not be affected if you decide not to be involved.

DIANE LEE
STUDY MIDWIFE

COUNTESS OF CHESTER HOSPITAL

CONSENT FOR TAKING PART IN A CLINICAL STUDY

HOW MUCH DO PREGNANT WOMEN KNOW ABOUT PRE-NATAL SCREENING TESTS?

I ..... (patient) have read and understood the explanation of the study which I have been invited to take part in by Diane Lee (Study Midwife). I have received, read and understood the explanatory leaflet that has been given to me and I agree to take part in this study.

I understand that I can withdraw from the study at any time, without having to give a reason. This will not affect my care now or in the future and I shall continue to receive treatment for my condition as appropriate.

Signed: .....

Dated: .....

I confirm that I have explained to the patient the nature and aim of the study.

Signed: .....
DIANE LEE

Dated: .....

March 1996

Maternal Serum Screening

Interview Guidelines

January 1996

RECORD NO

1	WHICH AGE GROUP APPLIES TO YOU ?	LESS THAN 20 21-30 31 AND OVER
2	OCCUPATION ?	
3	WERE YOU BOOKED BY A HOSPITAL OR COMMUNITY MIDWIFE ?	HOSPITAL COMMUNITY
4	WERE YOU OFFERED MATERNAL SERUM SCREENING FOR DOWNS SYNDROME ?	YES NO
5	DID YOU DISCUSS THE TEST WITH YOUR PARTNER ?	YES NO
6	DID A HEALTH PROFESSIONAL EXPLAIN THE TEST TO YOU	YES NO
7	WERE YOU GIVEN AN INFORMATION LEAFLET ?	YES NO
8	DID YOU HAVE THE TEST ?	YES / NO / UNSURE
9	WERE YOU AWARE THAT THIS TEST CANNOT **DIAGNOSE** DOWNS SYNDROME ?	YES NO
10	WERE YOU AWARE THAT THE TEST CAN PRODUCE FALSE POSITIVES ?	YES NO
11	WERE YOU AWARE THAT THE TEST CAN PRODUCE FALSE NEGATIVES ?	YES NO
12	IN THE UNLIKELY EVENT OF A POSITIVE RESULT,DID YOU KNOW THAT AN AMNIOCENTESIS WOULD HAVE BEEN DISCUSSED WITH YOU	YES NO
13	DID YOU KNOW THAT THERE WAS A SLIGHT RISK OF A MISCARRIAGE FOLLOWING AMNIOCENTESIS ?	YES NO
14	IF THE AMNIOCENTESIS DIAGNOSED DOWNS SYNDROME OR OTHER MAJOR ABNORMALITY - WERE YOU AWARE THAT A TERMINATION OF PREGNANCY WOULD HAVE BEEN DISCUSSED WITH YOU ?	YES NO
15	DID YOU KNOW THAT AMNIOCENTESIS RESULTS CAN TAKE UP TO 4 WEEKS	YES NO
16	WERE YOU AWARE THAT THE TEST WAS OPTIONAL ?	YES NO

Ultra Sound Scan

Interview Guidelines

January 1996

RECORD NO

1	WERE YOU OFFERED AN ULTRA SOUND SCAN?	YES	NO
2	DID YOU HAVE AN ULTRA SOUND SCAN	YES	NO
3	DID A HEALTH PROFESSIONAL EXPLAIN THE TEST TO YOU ?	YES	NO
4	WERE YOU GIVEN AN INFORMATION LEAFLET?	YES	NO
5	DID YOU DISCUSS THE TEST WITH YOUR PARTNER?	YES	NO
6	WERE YOU AWARE THAT THE PROCEDURE CANNOT DIAGNOSE **ALL** ABNORMALITIES?	YES	NO
7	WERE YOU AWARE THAT THE PROCEDURE CAN PRODUCE FALSE POSITIVES?	YES	NO
8	WERE YOU AWARE THAT THE PROCEDURE CAN PRODUCE FALSE NEGATIVES?	YES	NO
9	IF A MAJOR ABNORMALITY WAS DIAGNOSED,DID YOU KNOW THAT TERMINATION OF PREGNANCY WOULD HAVE BEEN DISCUSSED WITH YOU ?	YES	NO
10	WERE YOU AWARE THAT THE PROCEEDURE WAS OPTIONAL?	YES	NO
11	WHAT DID YOU CONSIDER THE MAIN PURPOSE OF AN ULTRA SOUND SCAN WAS?	SEE BABY	ANATOMY

12	The Decision to accept or reject pre-natal screening is often a difficult one. However, did you feel confident making that decision with the information given to you	**YES**	**NO**
13	Where did you feel that you obtained the most useful information regarding the tests? e g Midwife ,Doctor,Family/ Friends or Media		

Do you have any further comments about your experiences ?